JYU DISSERTATIONS 671

Virpi Mesiäislehto

Sexual and Reproductive Health and Rights through the Lens of Belonging

Intersectional Perspectives on Disability, Gender, and Adolescence in Tanzania

UNIVERSITY OF JYVÄSKYLÄ
FACULTY OF HUMANITIES AND
SOCIAL SCIENCES

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ABSTRACT

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This dissertation uses sexual and reproductive health and rights (SRHR) as a lens through which contextualized understandings of the intersection of disability, gender, and adolescence can be advanced, and discusses the current theoretical constructs of disability and development. The dissertation study counteracted the coloniality of knowledge production by exploring the perspectives of 199 Tanzanian adolescent females with disabilities. The theoretical inspirations of this qualitative abductive research were the social and human rights models of disability and the concept of intersectionality. I investigated cross-disability perceptions by using the participatory disability research approach and the method of empathy-based stories.

The findings, reported in three original research articles, show that realization of SRHR is based on a sense of humanness and belongingness. The notion of *belonging* was crucial for explaining the perspectives of the studied adolescents in the sense that sexual and reproductive health (SRH) entitlements are activated and sometimes constrained by belonging to familial and community networks. The notion of *becoming* in turn illustrated the potentiality of social personhood, which mediates inclusion and exclusion related to SRH, well-being, and entitlements. Additionally, singular understanding of adolescent SRHR was considered a disruption of the social norms of becoming, as were negative sexual and reproductive health outcomes. Together, these created a detrimental cycle that compromised the studied adolescents' belonging to the social networks that sustain their SRH. The study suggests that African communitarianism has the potential to reaffirm the worth of the studied adolescents while compelling moral obligations towards their SRH.

The theoretical and methodological contributions of this dissertation are based on empirical research. The existing models of disability are enriched by the thesis of belonging. Relational epistemic safe spaces are also proposed as a methodological approach for centering marginalized voices and revealing individualist, colonial, ableist, ageist, and gendered assumptions of voice in research and in international development practices. This contribution is timely, as disability inclusion is gaining momentum as a globalized development agenda and adolescent SRH face multiple challenges in Tanzania and beyond.

Keywords: disability, adolescence, Tanzania, sexual and reproductive health and rights.

ABSTRAKTI

Mesiäislehto, Virpi
Seksuaali- ja lisääntymisterveys ja -oikeudet yhteenkuuluvuuden kautta tarkasteltuna: Intersektionaalisia näkökulmia vammaisuuden, sukupuolen ja nuoruuden risteyskohdassa
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Tämä Tansaniaan sijoittuva väitöskirjatutkimus tarkastelee vammaisuutta kehityskysymyksenä seksuaali- ja lisääntymisterveyden ja -oikeuksien kautta. Se edistää intersektionaalista ja kontekstisidonnaista ymmärrystä vammaisuudesta, sukupuolesta ja nuoruudesta. Tutkimuksen teoreettisena inspiraationa hyödynnettiin vammaisuuden sosiaalista ja ihmisoikeusmallia. Tutkimus haastaa tiedonhankinnan kolonialiteetteja perehtymällä 199 tansanialaisen eri tavoin vammaisen tytön näkemyksiin. Tutkimuskysymyksiin etsittiin vastauksia laadullisen abduktiivisen tutkimusotteen ja osallistavan vammaistutkimuksen avulla. Vammaisten tyttöjen näkemyksiä tutkittiin eläytymismenetelmän kautta.

Tutkimusjulkaisuissa raportoidut tulokset osoittavat, että seksuaali- ja lisääntymisterveyden edellytykset perustuvat afrikkalaisesta humanismista kumpuavaan inhimillisyyteen. Tulosten mukaan yhteenkuuluvuuden käsite on ratkaiseva sen kannatellessa ja rajoittaessa seksuaali- ja lisääntymisterveyden ja -oikeuksien toteutumista. Globaalin pohjoisen määritelmät seksuaali- ja lisääntymisterveydestä sekä huonon seksuaali- ja lisääntymisterveyden vaikutukset voivat näyttäytyä esteenä sukupuolinormien mukaiselle sosiaaliselle kehitykselle ja vaarantaa yhteisöön kuulumisen. Tällöin osallisuus vammaisia tyttöjä kannatteleviin elintärkeisiin epävirallisiin tukiverkkoihin vaarantuu. Tutkimus viittaa siihen, että afrikkalaisella kommunitarianismilla on potentiaalia vahvistaa vammaisten tyttöjen ihmisarvoa samanaikaisesti, kun se asettaa moraalisia velvoitteita seksuaali- ja lisääntymisterveyden ja -oikeuksien toteutumiselle yhteisöissä ja perheissä.

Tutkimuksella on teoreettisia ja metodologisia kontribuutioita. Olemassa olevat vammaisuuden mallit saavat rinnalleen vammaisuuden yhteenkuuluvuuden mallin. Toiseksi tutkimus esittää yhteisöperustaisen episteemisen turvallisen tilan käsitteen syrjäytyneiden äänten esiintuomiseksi sekä individualististen, kolonialististen, ableististen ja sukupuolittuneiden oletusten haastamiseksi kehitystutkimuksen ja kansainvälisen kehityksen toimintakentällä. Nämä tutkimuskontribuutiot ovat ajankohtaisia vammaisinkluusion globalisoitumisen myötä sekä vammaisten tyttöjen seksuaali- ja lisääntymisterveyden ja -oikeuksien edistämisen kannalta niin Tansaniassa kuin laajemminkin.

Avainsanat: vammaisuus, nuoruus, Tansania, seksuaali- ja lisääntymisterveys ja -oikeudet

MUHTASARI

Mesiäislehto, Virpi
Afya ya uzazi na haki kupitia mrengo wa kukubalika katika kundi:
Mitazamo inayoingiliana juu ya ulemavu, jinsia, na ujana rika la balehe nchini Tanzania
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Tasnifu hii inatumia Haki ya Afya ya Uzazi (SRHR) kama mrengo ambao kwao uelewa wa muktadha wa muingiliano baina ya ulemavu, jinsia, pamoja na ujana wa rika la balehe vinaweza kutazamwa kwa pamoja, na kujadili mitazamo ya sasa ya kinadharia juu ya ulemavu na maendeleo. Utafiti wa tasnifu umeenda kinyume na dhana ya ukandamizaji unaozuia ugunduzi wa maarifa mapya kwa kutafiti mitazamo ya vijana 199 wa Kitanzania wa kike wenye ulemavu. Msukumo wa kinadharia nyuma ya utafiti huu ambao haukuwa na taarifa za awali juu ya uhalisia ulikuwa ni kutazama mkabala wa kijamii na wa haki za binadam katika ulemavu na dhana nzima ya muingiliano baina ya mikabla hii. Nilichunguza mitazamo juu ya ulemavu mtambuka kwa kutumia mbinu shirikishi ya utafiti wa ulemavu na mbinu ya simulizi toka kwa walengwa wenyewe.

Matokeo yaliyoripotiwa katika makala tatu za awali za utafiti, yanaonyesha kuwa SRHR inapata msingi wake katika utu. Dhana ya kukubalika katika kundi (belonging) lilikuwa muhimu kwa kueleza mitazamo ya vijana waliofanyiwa utafiti kwa maana kwamba stahiki zao juu ya Afya ya Uzazi (SRH) zinahuishwa ambazo wakati mwingine zimekuwa zikiminywa kwa wao tu kuwa sehemu ya familia na jamii kwa ujumla. Dhana ya kutakiwa kufikia viwango (becoming) kwa upande mwingine lilifafanua uwepo wa kutambuliwa kwao katika jamii, ambao huamua kipi kipewe nafasi kati ya dhana mbili za ujumuishwaji na utengwaji kuhusiana na SRH, hali bora, na stahiki. Zaidi ya hayo, uelewa haba wa SRHR kwa kijana wa rika la balehe ulionekana kuvuruga kawaida za uelewa wa jamii wa kufikia viwango, kwa kuleta matokeo mabaya juu ya afya ya uzazi. Kwa pamoja, matokeo haya yalileta uharibifu wa uelewa kwa vijana hawa waliofanyiwa utafiti, ambao wako kwenye mitandao ya kijamii inayowasaidia kuendeleza na kudumisha uelewa wao juu ya SRH. Utafiti unapendekeza kwamba falsafa ya kiafrika ya utu ina uwezo wa kuthibitisha tena thamani ya vijana hawa waliofanyiwa utafiti huku ikilazimisha wajibu wao wa kimaadili ili kulinda afya zao za uzazi.

Michango ya kinadharia na kimbinu ya tasnifu hii imejikita katika utafiti juu ya vitu halisi vilivyowahi kufanyika. Mikabala iliyopo ya ulemavu imeboreshwa na nadharia yenye msingi wake katika ukubalikaji. Kuhusisha falsafa za maarifa ambapo watu wanakuwa huru kujadili masuala mbalimbali kunapendekezwa kama mbinu ya kuingiza sauti zilizotengwa na kufichua ubinafsi, kujitukuza, kujivuna, kujikweza, na dhana ya nani mwenye sauti kijinsia katika tafiti na katika shughuli za maendeleo ya kimataifa. Mchango huu umekuja kwa wakati muafaka, ambapo ushirikishwaji wa watu wenye ulemavu unazidi kushika kasi kama ajenda ya dunia ya maendeleo, vilevile afya ya uzazi kwa vijana wa rika la balehe inakabiliwa na changamoto nyingi nchini Tanzania na kwingineko.

Maneno nanga: ulemavu, ujana wa rika la balehe, Tanzania, afya ya uzazi na haki.

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Communities in Tanzania and Finland have poured their time, ideas, patience, comments, edits, and love into this dissertation. I would like to emphasize and assure the reader that all that is advantageous in this dissertation is the product of collaboration.

During this five-year journey, I asked myself these questions:

> How am I contributing today?
>
> By sitting at my desk, growing my brain
>
> How is this healing the world?[1]

In my attempt to answer the above questions, my thought process always ends with the participants of this study. This research only provides a small glimpse into their social world(s), but the stories are theirs. I ensured the participants a safe space for their stories as I wanted to value their perspectives. Thus, I'd like to begin this list of acknowledgements by expressing my deepest appreciation to the 199 Tanzanian adolescent girls with disabilities who participated in this study. I've done my utmost to do justice to your views. Without you, this dissertation wouldn't have been possible or worthwhile.

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[1] From a poem "Tension" by doctoral student Michelle Redman-MacLaren

I'd like to express my gratitude to the Tanzanian organizations of persons with disabilities that work tirelessly towards the well-being of persons with disabilities in Tanzania at national, regional, and district levels. I especially extend my thanks to SHIVYWATA for its willingness to partner with me in this research, and for providing your networks and expertise for my use. I'd especially like to thank the following people from the Tanzanian disability movement for their leadership during this research: Jonas Lubago, Elisha Milia, Dickson Mveyange, and Ndikirwa Pallangyo. I look forward to future collaboration with you and to seeing the outcomes of our research findings as they continue to be disseminated.

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A researcher is always a researcher through others. Pursuing a PhD from a distance, without long-term presence in an academic community has been a lonely journey. For this reason, I especially enjoyed the fall of 2019, when I spent several months in Ilokivi and experienced the benefits of an academic community. If it wasn’t for the in-person and online development studies’ doctoral seminars, I’d have had no useful critique to improve my dissertation. Dr. Elina Jokinen, aka ‘the thesis whisperer’, brought the academic writing process to life. Recognizing the four seasons of a writer helped me immensely. I’d also like to thank Magdaleena Lehmuskoski for her co-authorship, peer inspiration, and for making my PhD journey less lonely. Above all, you are a dear friend.

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Arusha, Tanzania 23.5.2023
Virpi Mesiäislehto

FIGURES

TABLES

ACRONYMS

AIDS	Acquired immunodeficiency syndrome
COSTECH	Tanzania Commission for Science and Technology
HIV	Human immunodeficiency virus
ICPD	International Conference on Population and Development
NIMR	National Institute of Medical Research
SDG	Sustainable Development Goals
SHIVYAWATA	Shirikisho la Vyama Vya Watu Wenye Ulemavu Tanzania, The Tanzania Federation of Disabled People's Organizations
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
STI	Sexually transmitted infection
UN CEDAW	United Nations Convention on the Elimination of Discrimination against Women
UN CRC	United Nations Convention on the Rights of the Child
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities
UN	United Nations
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNPRPD	United Nations Partnership for the Rights of Persons with Disabilities
URT	United Republic of Tanzania
WHO	World Health Organization

ANNEXES

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1 INTRODUCTION

This dissertation is positioned at the nexus of two scholarly traditions of development and disability studies. It investigates the intersection of disability and female adolescence in the context of sexual and reproductive health and rights in Tanzania[2]. It uses the sexual and reproductive health and rights of adolescent females with disabilities in Tanzania as an area of research that reflects broader theoretical concerns related to disability and development. This dissertation has two intertwining components: First, the argument that the current theoretical constructs used to study disability and development must be reconsidered from a global South perspective and a proposal of how this might be done; and second, the findings of an empirical study on access to the sexual and reproductive health and rights of adolescent females with disabilities in Tanzania.

I begin this chapter with a background to disability in the context of development. Next, I present the sexual and reproductive health and rights of adolescents as an international development and policy concern. This is followed by justifications for the relevance of this topic. After this, I present the aims and research questions of my dissertation, and a brief overview of the methodology. I conclude the chapter by describing the structure of the summary of the dissertation.

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[2] What is known officially as the United Republic of Tanzania (the URT) is a nation consisting of the Tanzania mainland and the Zanzibar archipelago. Zanzibar is a semi-autonomous territory that is in political union with mainland Tanzania. It has somewhat unique cultural and socio-political characteristics, and legal and policy frameworks related to disability and sexual and reproductive health and rights. This dissertation focuses on mainland Tanzania and uses 'Tanzania' throughout the text to indicate the geographical scope of the study. When the URT is mentioned, the data referred to are from both Zanzibar and Mainland Tanzania due to the unavailability of mainland-specific data.

1.1 Background of the study

Despite having the same sexual and reproductive health needs and rights and being as sexually active as their peers, women and girls with disabilities in the global South have typically been excluded from access to sexual and reproductive health and rights (Casebolt, 2020; Hameed et al., 2020; Matin et al., 2021). There are widespread false beliefs that persons with disabilities have few or no sexual rights, do not need as much sexual and reproductive health care as persons without disabilities, are not desirable as sexual partners, or are non-sexual (Casebolt, 2020; Hameed et al., 2020; Hunt et al., 2017; Rohleder et al., 2019; Wilbur et al., 2019). The stigmatization of the sexuality of persons with disabilities begins early. It is shaped by social and cultural negative and dismissive attitudes (McKenzie, 2013; Mckenzie & Swartz, 2011) and perpetuated by communities, educators, and health care providers (Bangura et al., 2021; Hunt et al., 2017; Meer & Combrinck, 2015; Sanga et al., 2022). Relatives, teachers, and health care providers are often untrained and feel uncomfortable discussing sexuality with young persons with disabilities (Ballan, 2012; Sanga et al., 2022; Tugut et al., 2016). Moreover, persons with disabilities are invisible in most sexual and reproductive health policies (Addlakha et al., 2017; Trani et al., 2011), interventions (Hameed et al., 2020) and research (Amin et al., 2020); and the intersection of adolescence and disability is rendered even more invisible (Bastable et al., 2020; Obasi et al., 2019; Rugoho & Maphosa, 2020).

The models and definitions of disability are strongly influenced by historical, research, international development and human rights paradigms, which are often intertwined when it comes to disability and development. The use of *the human rights model of disability* (Degener, 2016; Quinn & Degener, 2002) has rapidly increased globally (Lawson & Beckett, 2021), intertwining the fields of disability and development (Series, 2020). The human rights model of disability is framed by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) (2006), and is first and foremost a model for disability policy that provides guidance and requirements for policy responses to disability (Lawson & Beckett, 2021). According to the UN CRPD, 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"(Article 1, United Nations, 2006). This definition of disability is used throughout this dissertation.

The social model of human rights for persons with disabilities builds on the strengths of the social model of disability and the human rights model of disability (Berghs et al., 2019; Lawson & Beckett, 2021). The social model shifts attention from the individual's impairment to the environment that disables them (Finkelstein, 1980; Oliver, 1983, 1986, 1996). It claims that impairments as such are not disabling, but that the various structural, cultural and social barriers in society, which may be related to attitudes, physical environments, or communication, make the disability manifest in the lives of individuals (C. Barnes, 2020). The social model of human rights for persons with disabilities draws from the perspective that “a new stronger social tool for justice, rights and entitlements in society” is needed, as disabling neoliberal politics have negatively affected persons with disabilities all over the world (Berghs et al., 2019, p. 1037). The social and human rights models complement each other in the sense that the social model is a descriptive and heuristic device that inspires us to determine the barriers experienced by persons with disabilities in diverse contexts, and the human rights model is a model of disability policy (Lawson & Beckett, 2021). In line with abductive methodology (Timmermans & Tavory, 2022), the social model of human rights for persons with disabilities provides this study a loose theoretical framework to inspire research discoveries in the social context of Tanzania.

Although the UN CRPD has framed the efforts on advancing the well-being of persons with disabilities globally, the lived realities of majority of world’s persons with disabilities living in the global South are often devastating. In this vein, persons with disabilities in Tanzania are often among the most marginalized. Despite Tanzania being a forerunner in the East African region in frameworks governing the rights of persons with disabilities (Mitra, 2018), the policies and everyday realities are significantly disconnected, especially when it comes to the sexual and reproductive health and rights of adolescent females with disabilities.

Adolescents’ sexual and reproductive health and rights are a gendered, critical area in international development (Darroch et al., 2016; Patton et al., 2016; Starrs et al., 2018). The urgency of the issue is illustrated by the fact that half of the pregnancies of adolescent females aged 15–19 in the global South are unintended (Darroch et al., 2016). The inequalities in adolescents’ sexual and reproductive health and rights often remain strong and under-researched among those in the outermost margins of society (McGranahan et al., 2021; Melesse et al., 2020; Nowshin et al., 2022). Multiple sexual and reproductive health and rights adversities, such as unwanted pregnancies (Hokororo et al., 2015; McCleary-Sills et al., 2013), early marriages (Stark, 2018), and gender-based violence (Stöckl et al., 2014) force Tanzanian children directly into adulthood, leaving them with no opportunities to experiment, develop, and explore adolescence. The advancement of the adolescent sexual and reproductive health and rights agenda faces multiple challenges in Tanzania (Bylund et al., 2020; Hokororo et al., 2015; Mbuya-Brown & Beardsley, 2018; Nyblade et al., 2017). Like in many other contexts in which individuals are understood in relation to others, and sexual and reproductive health, well-being, and entitlements are primarily not understood as rights (Standing et al., 2011; Undie & Izugbara, 2011), in Tanzania human rights often face opposition, as they are perceived as decontextualized (S. A. Kelly et al., 2022) and disrupt social norms (Fay, 2019). Furthermore, the complex landscapes related to sexual and reproductive health and rights cut across the legal, religious, human rights, and public health discourses in Tanzania (Sambaiga et al., 2019).

1.2 Motivation for the study

As the momentum of disability inclusion as a globalized development agenda gathers, development interventions in sexual and reproductive health and rights of persons with disabilities are expected to increase. Tanzania is an interesting study context for multiple reasons. First of all, sexual and reproductive health and rights are under-researched and overshadowed by contradicting political, policy and social norms (Bylund et al., 2020; Sambaiga et al., 2019). Second, Tanzania is strongly committed to advancing the rights of persons with disabilities, yet advances in sexual and reproductive health and rights remain limited when it comes to policy and programming (Massay, 2021). Third, demographically Tanzania is one of the youngest countries in the world with an expanding adolescent population, expected to double by 2050—a population that is about to reach or has already reached reproductive age (United Republic of Tanzania, 2018). Thus, addressing adolescent sexual and reproductive health and rights in a way that reduces social inequalities will have an enormous impact on the future of the nation (Neal et al., 2020).

This dissertation is motivated by how in Tanzania the legal and policy frameworks are deeply disconnected from the lived realities of adolescent females with disabilities. The frameworks upholding the sexual and reproductive health and rights of adolescent females with disabilities in Tanzania are either constrained by a medicalized view of disability, a dilution of the unique aspects related to the intersection of female adolescence and disability, or their limited ability to contain aspects pertinent to the Tanzanian context. Social and cultural norms problematize these frames as a perceived threat to the well-being of the very population whose rights they are meant to uphold (Fay, 2019). Furthermore, while individualization and liberal politics continue to deliver certain segments of the population from conventional gendered structures, others are becoming increasingly affected by inequalities (Arnot, 2009; Arnot et al., 2012).

The dissertation was also motivated by a rhetorical, multifaceted question: "Is Tanzania ready for sexual and reproductive health and rights as a singular normative order of sexual and reproductive well-being?". First of all, this question emphasizes the contested nature of sexual and reproductive health and rights. It illustrates the obligatory nature of the human rights conventions that flow from the global level to the national and subnational, demonstrating the direction of the extraterritorial stipulations in the name of development. The North–South direction is also implied in the global North dominance in disability theorizations across academia, including the increasingly globally applied human rights model. However, global North-oriented models, including that based on the UN CRPD have been criticized for neglecting aspects pertinent to disability in global South contexts (Grech, 2011b; Meekosha, 2011) such as Tanzania. Second, the question leads to further questions: "Which rights?" and "Whose rights in particular"? These are critical, illuminating questions and encourage the exploration of the particularly contested adolescent sexual and reproductive health and rights in Tanzania. The taboo subject of sexuality and the sexual lives of persons with disabilities (Carew et al., 2017) adds another layer of complexity to understanding, accepting, discussing, and upholding this constellation of rights.

In addition to this deep disconnection between rights and realities, this dissertation is motivated by recent empirical advances that have resulted in novel disability theorizations emerging from the global South and from Africa in particular. According to Rao and Kalyanpur (2020, p. 1845), recent empirical disability research and the postcolonial literature highlight ways of addressing the shortcomings of recognizing, valuing and building on local knowledge and practices related to disability. The focus should primarily be on the epistemic standpoints and experiences of persons with disabilities in the local contexts (also in Bezzina, 2018; Ned et al., 2022; Tlostanova & Mignolo, 2012), and after this they should emphasize the available strengths and resources related to the local conceptualizations of disability and disability-related practices (also in Aldersey, 2012b; Harry, 2020).

Another important motivation behind this study was the scarcity of research on the sexual and reproductive health and rights of persons with disabilities, as well as the methodological and ethical particularities related to conducting research on persons with disabilities (Amin et al., 2020). Overcoming the methodological challenges related to researching adolescents with disabilities in contexts in which they are seldom encouraged to express themselves was certainly one of the key motivations of this study (Baird, Camfield, Ghimire, et al., 2021; Facca et al., 2020; Mechanic, 2013; Mills, 2020; Odeh et al., 2021; Pincock & Jones, 2020; Wickenden & Kembhavi-Tam, 2014).

Certain life events and experiences may affect the way in which a researcher is drawn towards a research topic. I have lived in Tanzania for nine years. I initially arrived as an international development professional. During these years, I have spent a considerable amount of time with adolescents and adults with disabilities, and with their caregivers, and have become familiar with the harsh everyday realities many of them face, although I do not share the experience of disability with them. Some of them have stayed with me through their stories and personal interactions, illuminating the complex, multi-layered social worlds with which they are intertwined. Furthermore, during my years in Tanzania, I have collaborated with various civil society stakeholders such as organizations representing persons with disabilities, faith-based organizations, and government stakeholders. Through these encounters and experiences, I have come to understand that it is not the lack of policies and laws that causes the harsh realities of many adolescents with disabilities in Tanzania, but the inability to influence change in the social norms that negatively affect persons with disabilities. At the same time, I have observed the strengths of close-knit communities and have had the privilege to enjoy and contribute to mutual reciprocity over the years.

Sometimes, research topics seem to choose us. My personal life experiences have also motivated this study. Growing up in Finland, which is one of the safest places in the world in which to be pregnant and give birth, led me to reflect on my privileges related to sexual and reproductive health and rights early on in life. I have experienced first-hand the profound impact sexual and reproductive health services can have on the life of an individual; in my case on the mother and a child. First, through the stories my mother has told me about her fear of losing me while pregnant, and the quality health care intervention she had access to which eventually saved my life. Second, my positive personal experiences later on in life as a sexual and reproductive health service user in Finland, in some of the most intimate, significant, and life-changing times of my life. These, as well as my professional aspirations related to addressing the global and local inequalities related to sexual and reproductive well-being, also greatly motivated me to conduct this research.

1.3 Research aims and questions

Based on the theoretical, conceptual, and contextual background, and the motivations presented above, this study addresses the broader research question of how Tanzanian adolescent females with disabilities perceive their sexual and reproductive health and rights. The three research questions were:

- How do the perspectives of adolescent females with disabilities portray collective dynamics as sustaining and constraining their sexual and reproductive health and rights?
- How do the studied adolescents' perspectives demonstrate the logics of inclusion and exclusion within sexual and reproductive health and rights?
- How could the intersectional perspective of disability and female adolescence inform the realization of sexual and reproductive health and rights in Tanzania?

When combined, the research questions form a contextualized exploration of the kind of conceptualizations of disability and development that can be discovered through the intersectional lens of disability and female adolescence. Furthermore, these questions also enable using sexual and reproductive health and rights as a lens through which to investigate in depth the current theoretical constructs in disability and development.

In response to the research questions and as a contribution to remedying the gaps in the existing theories and literature, this dissertation counteracts the coloniality of knowledge production by exploring and presenting the marginalized perspectives of Tanzanian adolescent females with disabilities of their sexual and reproductive health and rights. The research applied an abductive qualitative research methodology (Timmermans & Tavory, 2022), and the participatory disability research approach (Katsui & Chalklen, 2020). The empathy-based story method

(Eskola, 1997; Särkelä & Suoranta, 2020; Wallin et al., 2015, 2018) was used to investigate the perceptions of 199 Tanzanian adolescent females with different disabilities. The dissertation consists of three academic articles based on empirical research conducted in Tanzania in 2019–2022 and a dissertation summary.

I was the main contributor in the three original, peer-reviewed publications in terms of conceptualization[3], data curation[4], investigation[5], methodology[6], project administration[7], and writing the original and final drafts[8,9].

- Article I: Mesiäislehto, V., Katsui, H., & Sambaiga, R. (2021). Disparities in Accessing Sexual and Reproductive Health Services at the Intersection of Disability and Female Adolescence in Tanzania. *International Journal of Environmental Research and Public Health*, 18(4), 1657. https://doi.org/10.3390/ijerph18041657
- Article II: Mesiäislehto, V. (2023). Rethinking gender-based violence in the context of access to sexual and reproductive health services: Perceptions of adolescent females with disabilities in Tanzania. *Forum for Development Studies*. [in review].
- Article III: Mesiäislehto, V., Lehmuskoski, M., Katsui, H. & Sambaiga, R. (2022). Menstrual pain realities of young females with disabilities in Tanzania: Towards a nuanced understanding of pain and embodiment. In H. Katsui & V. Mesiäislehto (Eds.), *Embodied Inequalities in Disability and Development* (Vol. 1–Book, Section, pp. 35–61). African Sun Media, Stellenbosch, South Africa.

The summary of the dissertation is organized as follows. After the introduction to the topic in this chapter, I move on to Chapter two to describe the characteristics pertinent to the Tanzanian cultural and socio-political landscape at the interface of disability and sexual and reproductive health and rights. Chapter three provides an account of the theoretical inspirations underpinning my study and definitions of the central concepts used. In Chapter four, I present the methodology that generated the empirical grounds of my dissertation. Chapter five presents an outline of the research articles that constitute the dissertation and an overall summary of their findings. In Chapter six, I return to the research questions and discuss reconceptualizing and reimagining disability justice from an Afrocentric standpoint, which would better address sexual and reproductive health, well-being, and entitlements in Tanzania. I present the methodological contributions of the dissertation by advancing the notion of epistemic safe spaces. Recognizing the increasing momentum related to the globalizing trend of disability inclusion, I then outline the contributions of the dissertation to development policies and practices. At the end, I draw conclusions and provide suggestions for future research.

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[3] Hisayo Katsui contributed to the conceptualization of Articles I and III.
[4] Magdaleena Lehmuskoski contributed to the data curation for Article III.
[5] Magdaleena Lehmuskoski contributed to the investigation for Article III.
[6] Magdaleena Lehmuskoski contributed to the methodology for Article III.
[7] Richard Sambaiga contributed to the project administration for Articles I and III.
[8] Magdaleena Lehmuskoski contributed to the writing of the first draft of Article III.
[9] Hisayo Katsui contributed to the reviewing and edits of Article I.

2 SETTING THE SCENE: DISABILITY, GENDER, ADOLESCENCE, AND SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS IN TANZANIA

This chapter addresses the context of disability, gender, adolescence and sexual and reproductive health and rights in Tanzania. It describes the unique characteristics of the Tanzanian cultural and socio-political landscape at the interface of disability and sexual and reproductive health and rights. I start by broadly reflecting on sexual and reproductive health and rights in Tanzania from the perspective of gender, disability, and adolescence, and then the policy and legal frameworks governing the rights of adolescent females with disabilities. Finally, I reflect on the Tanzanian cultural and social norms of disability, gender and adolescence as a possible explanation for why the policy and legal framework cannot inspire social change for the benefit of this population.

Tanzania is a former colony of Germany and Great Britain and is a unique nation in the East African region due to its abundant natural resources, relatively stable politics, and long-standing peace. Since its independence in 1961, the post-colonial policies related to language and economics have resulted in rather limited external linguistic and cultural influences and have set an inherently Tanzanian context for disability, gender, adolescence, and the sexual and reproductive health and rights of the nation. Tanzania, with its population of 61.7 million (URT, 2022), faces considerable difficulties in terms of fulfilling its commitments to reach equality, most visibly in the areas of health, education, and income. The URT reached a milestone in 2020 when it became a lower-middle-income country in accordance with the targets of the Tanzania Development Vision 2025. This economic development has not, however, led to equal social and economic progress. The nation stands at 163 out of 189 in the 2020 Human Development Index and is ranked at 131 out of 193 countries in the Sustainable Development Goal Index 2020. Although these rankings do not provide a comprehensive picture of the development of the nation, they can still be used to illustrate where the URT stands in comparison to other countries.

Gender is one of the key factors causing inequalities. Women's literacy rate (73.1 percent) is lower than that of men (83.2 percent). Women's political participation is also much weaker than that of men, with 36.9 percent of female participation in Parliament versus 63.1 percent , respectively (Schwab et al., 2019). Furthermore, maternal mortality remains high at 524, and only half of women have a minimum of four antenatal care visits (Schwab et al., 2019). Inequalities are strong along the urban–rural divide and women living in rural areas are excluded from services and opportunities; for instance, the total fertility rate in rural areas is 6 and in urban areas, 3.8. (URT, 2016b).

2.1.1 Disability in Tanzania: A divine plan, medical curiosity, and an occupier of civic space

Persons with disabilities are not a well-defined minority group; they are an ambiguous demographic in Tanzania. The concept of disability is fluid because the types of disability vary and the experience of disability can vary from intermittent through temporary to long-term. This ambiguity is compounded by disability-related stigma, and consequently, some individuals and households prefer not to associate themselves with disability or representative organizations of persons with disabilities or participate in research on disability (de Groot et al., 2022; Goodall et al., 2018; Groce, 2006; Lund & Roberts, 2018). According to the 2017–18 Tanzania Household Budget Survey data, 6.3 percent of Tanzanians are persons with disabilities (URT, 2019) and 13.2 percent of households have at least one member with disabilities (URT, 2008). The prevalence of disability varies greatly between regions (URT, 2012b). Among women, it is 7.8 percent and among men, 5.7 percent. However, no significant difference has been found between boys and girls (URT, 2019).

Among children and young people (aged 5–24), the disability prevalence rate is 2.3 percent (United Nations Children's Fund [UNICEF], 2021). Of all Tanzanian children and young people aged 5–24, 1.7 percent have difficulty remembering, 1.5 percent have difficulty seeing, and 1.3 percent have difficulty hearing, 1.2 percent have difficulty communicating, walking and caring for themselves, and 0.6 percent are living with albinism[10] (UNICEF, 2021; URT, 2019). Disability prevalence increases in adulthood and rises steeply among older adults, an increase that starts in the 20- to 24-year age group (Includovate, 2021; UNICEF, 2021). Disability data of this kind from censuses and surveys should be considered with caution, as definitions of disability vary. Moreover, cultural beliefs and attitudes towards disability in particular contexts influence how disability is

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[10] Since 2008, Tanzania has used the Washington Group Short Set of Questions (WG-SS) in selected surveys to collect data on disability. This method addresses the challenge of measuring disability in a relatively standardized, culturally neutral manner. The WG-SS covers six functional domains or basic actions: seeing, hearing, walking, cognition, self-care, and communication (Madans et al., 2011).

elicited in survey and census questions and how these questions are responded to (Groce, 2006).

The majority of Tanzanian persons with disabilities navigate through life in a context of structural, cultural, and economic oppression. They do so with almost no direct support from the Tanzanian government, relying on family and the community (Aldersey, 2012b; Kuper et al., 2016), and assistance from national and local non-governmental organizations funded by external donors (Includovate, 2021; Lee, 2012). The existing evidence shows that more persons with disabilities live in poor households (20%) than those without disabilities (12%) (Simeu et al., 2018), and that households headed by persons with disabilities are among the poorest in Tanzania (URT, 2012a).

In terms of education, learning environments do not respond well to the characteristics of children and youth with disabilities (Lehtomäki et al., 2014; Mapunda et al., 2017; Matonya, 2016). For instance, in 89 percent of schools, toilets are not accessible for students with physical or visual disabilities (UNICEF, 2021). Moreover, only 49 percent of children with a disability complete primary school compared to 83 percent of children without disabilities (Simeu et al., 2018). In terms of health, access to health insurance is limited (Includovate, 2021; UNICEF, 2021). Lack of access to rehabilitation services, malnutrition, and exclusion from immunization programs are some of the grave health issues that affect the health status of children and young persons with disabilities throughout their lifespan (UNICEF, 2021). Moreover, Tanzanian adolescents with disabilities tend to experience more mental health problems and depression than their peers without disabilities (Quinones et al., 2021).

Other disability-related aspects in Tanzania are the high prevalence of obstetric fistulae (Fiander & Vanneste, 2012): over 46,000 Tanzanians live with this condition (Tanzania, 2010). In addition, one in ten Tanzanian girls undergo female genital mutilation (URT, 2016b). Obstetric fistulae and female genital mutilation may be categorized as physical and/or sexual disability (Owojuyigbe et al., 2017). Albinism is considered a disability in Tanzania, and persons with albinism have been targeted by witchcraft-inspired violence, killings, and social marginalization (de Groot et al., 2019, 2022; Tanner, 2010; URT, 2016a). Albinism is often compounded with partial vision (Grønskov et al., 2007) and environmental barriers, such as damage to the skin and eyes caused by the sun's ultraviolet radiation. Financial resource constraints related to purchasing sunscreen and hats exacerbate the disability. Lack of spectacles for those with partial vision can also cause disability when impairments interact with financial deficits. The members of the deaf community in Tanzania selectively associate themselves as persons with disabilities, typically when doing so provides access to resources and connections (Lee, 2012). These aspects of disability in Tanzania demonstrate that disability should indeed be understood as relational and as interacting with the context and environment (Katsui & Chalklen, 2020).

Different conceptualizations of disability based on culture and religion also influence how persons with disabilities are perceived and treated by their communities. Here I present four notable disability models that co-exist and continue to evolve in Tanzania (Brocco, 2015; Falola & Hamel, 2021; UNICEF, 2021). The *spiritual model of disability* associates the person with the disability or a family member with sin or wrongdoing (Masanja, 2015; Stone-Macdonald, 2012). Despite the development of modernization and moderate secularization in Tanzania, spiritual aspects are being regenerated and reattached to disability, and witchcraft-related sexual acts and the body parts of persons with disabilities continue to be associated with wealth and success (de Groot et al., 2022; Groce & McGeown, 2013; Groce & Trasi, 2004; UNICEF, 2021). Distinguishing religion from spirituality is important here, as it is noteworthy that religion plays an important role in the everyday lives of Tanzanians and determines decision-making and attitudes (Mukandala, 2006), also when it comes to disability. Spirituality and indigenous belief systems are intertwined with Islam and Christian faith, and produce new meanings for disability together with Western biomedical views (Brocco, 2015).

The charity model perceives persons with disabilities as objects of charity and reduces their agency and autonomy by, for instance, infantilizing them (Mattioli, 2008). The charity model is also associated with community and family responsibility for providing and caring for those in need, which is deeply embedded in the *ubuntu* world view of Swahili culture (Rettová, 2020) and has been argued to sustain the well-being of persons with disabilities (Bannink Mbazzi et al., 2020; Katsui, 2012; Katsui & Mesiäislehto, 2022). *Ubuntu* is a central concept of African humanism and refers to humanity that entails moral obligations (Rettová, 2021). *The medical model* of disability is also a prevalent way of conceptualizing disability in contemporary Tanzania, and focuses on medicalizing disability by seeking a cure for it (Aldersey, 2012b; Mattioli, 2008). *The social model of disability*, perceived by some as a predecessor to *the human rights model of disability* (Berghs et al., 2019; Lawson & Beckett, 2021), is a more recent approach. The two latter approaches are mostly visible at the formal level, in laws, policies, and the civic spaces where disability rights are discussed by organizations of persons with disabilities and international development agencies.

Although disability in Tanzania often has negative connotations, such as a burden or curse (Aldersey, 2012a; Stone-Macdonald, 2012), in contemporary Tanzanian culture some divergent, positive conceptualizations of persons with disabilities as, for example, treasures from God (Stone-Macdonald, 2012), sources of happiness (McNally & Mannan, 2013) and having unique talents (Kisanji, 1995) exist. This may arise from precolonial African beliefs that disability was not only something negative, and persons with disabilities were accepted in society (Ojok & Musenze, 2019). In Tanzania, social norms related to disability seem to be changing (Quinones et al., 2021). For instance, the everyday language used to talk about persons with disabilities is gradually moving away from the *ki-vi* noun class—typically used for non-humans or objects—to the *m-wa* noun class. The increasing use of person-first language, *watu wenye ulemavu* (people with disabilities), may indicate a change towards seeing persons with disabilities first and foremost as people (Brocco, 2015), and may be a result of adopting international person-first vocabularies.

The disability movement in Tanzania is built around representative organizations of persons with disabilities and is relatively well established (Inclusive Development Promoters and Consultants [IDPC], 2021; Sida, 2014a). Organizations of persons with disabilities provide a respected forum in which persons with disabilities can gather, and a space that participants utilize for making useful connections (Lee, 2012). The Tanzania Federation of Disabled People's Organizations, *Shirikisho la Vyama Vya Watu Wenye Ulemavu Tanzania* (SHIVYAWATA), regularly takes part in discussions with the government. The Federation brings together ten member-based national organizations of persons with disabilities that have regional and district representation. The shared experience of disability among the members of organizations of persons with disabilities promotes a certain solidarity, but other researchers have identified representation politics and competition over scarce resources within and between Southern organizations of persons with disabilities (Berghs, 2012; Bezzina, 2020; Katsui, 2012; Lee, 2012). The disability movement, especially the leadership, is quite homogeneous, meaning that although the women's departments of these organizations are typically led by women, the top leadership mostly consists of older males. The civic spaces occupied by organizations of persons with disabilities is not fully inclusive of women with disabilities, persons with intellectual disabilities, adolescents, or yong people. This narrows the representation of persons with disabilities and their mobilization opportunities. The status of persons with disabilities described here, including their inequality, rejection, violence, and mistreatment, as well as the Tanzanian understanding of disability, could also be considered "symptoms of colonial encounters and the resultant material conditions and injustices" (Ned, 2022, p. 498).

2.1.2 Disability and adolescence: An invisible, ambiguous, yet increasingly recognized intersection

In demographic terms, Tanzania is one of the youngest countries in the world, with 50 percent of the population being under the age of 18 (United Republic of Tanzania, 2018). The number of adolescents (aged 10–19) is projected to double by 2050, from 13.2 million to 28 million (ibid.). Tanzania has one of the highest adolescent fertility rates in the world, which has recently increased from 116 in 2010 to 132, according to the Tanzania Demographic Health Survey 2015-16 (URT, 2016b). Approximately 27 percent of Tanzanian girls aged 15–19 are either mothers or pregnant (URT, 2016b). They lack knowledge of sexual and reproductive health (Hokororo et al., 2015) and access to sexual and reproductive health services (Bylund et al., 2020; Mchome et al., 2015; Nyblade et al., 2017). Only 30 percent of health service delivery meets the national standards for adolescent-friendly health services (URT, 2018). Moreover, female adolescents in Tanzania have a high frequency of child marriage, as one in three women marry before the age of 18 (URT, 2016b). These negative sexual and reproductive health service outcomes are associated with socially normalized sexual exploitation of adolescents (Abeid et al., 2014; Howard-Merrill et al., 2022; McCleary-Sills et al., 2013;

Mlyakado & Li, 2019). Teenage pregnancies and adolescent girls' HIV infection rates are major public health concerns in Tanzania.

Like disability, adolescence is an ambiguous concept in Tanzania, which is indicated by, for instance, Kiswahili having no equivalent term. However, the "adolescent" is the term mainly utilized in the international development forums. Stark (2018) proposes that adolescence, according to the social constructivist view, is not always granted to girls and young women; it depends on the family's economic status. Adolescence in Tanzania can therefore be understood "as a socially approved, post-puberty time of financial dependence on one's birth family" (Stark, 2018, p. 898). Adolescence may thus be experienced only by those whose families are in a position to provide for their offspring's schooling and meet their other financial needs. If no such means exist, girls and young women are denied the period of adolescence, and the transition to adulthood happens more quickly. Early marriage or sexual favors to men may become ways with which the girls can reach and display financial independence or make financial contributions to their families.

The intersection of adolescence and disability is largely unexplored in Tanzania, and only a few studies have examined it (Mbwilo et al., 2010; Quinones et al., 2021; Sanga et al., 2022). Furthermore, the sexual and reproductive health status of adolescents with disabilities in Tanzania remains largely unknown. It has been suggested that negative adolescent sexual and reproductive health outcomes are exacerbated by disability (UNICEF, 2021). The evidence available from the African continent demonstrates that adolescents with disabilities have unique, and at times greater, needs for sexual and reproductive health services but that they often face challenges when trying to access them (Burke et al., 2017; Obasi et al., 2019; Rugoho & Maphosa, 2020). Reaching menarche and the onset of menstruation is considered a dual burden for young females with disabilities (Wilbur et al., 2019). Socially normalized gender and disability-based violence has been evidenced, yet remains an invisibilized, underexplored and silent emergency that cuts across Tanzanian society (ADD International, 2016; Greenwood et al., 2016; Includovate, 2021; Quinones et al., 2021; UNICEF, 2017, 2021). Furthermore, the lack of information on sexual and reproductive health (Burke et al., 2017), unwanted pregnancies (Obasi et al., 2019), and HIV and AIDS (Groce & Trasi, 2004; Hanass-Hancock, 2009, 2009) have detrimental implications for the future of these young females, and result in further exclusion and lost opportunities.

The social and gender norms related to disability, adolescence and sexuality influence the way in which the sexual and reproductive health and rights of adolescent females with disabilities are perceived in society. Adolescent sexuality and the sexuality of persons with disabilities is considered a taboo (Bylund et al., 2020; Carew et al., 2017; Mchome et al., 2015; Nyblade et al., 2017; Rohleder et al., 2019; Sanga et al., 2022). Stigma towards adolescents in sexual and reproductive health services is evident in Tanzania, and it hinders their access to these essential services (Mbeba et al., 2012; Nyblade et al., 2017). The misconceptions and cultural taboos related to disability, sexuality, and adolescence are understood to be the reason behind many of the abovementioned sexual and reproductive health service disparities (UNICEF, 2021). The development sector and the emerging efforts in the civic space in collaboration with the organizations of persons with disabilities have recently directed attention towards and addressed the sexual and reproductive health and rights at the intersection of disability, gender and age (Includovate, 2021; Lutheran World Federation, 2021; United Nations Population Fund [UNFPA], 2021; UNICEF, 2021).

2.1.3 Opportunities and limitations of legal and policy frameworks

The government of Tanzania has shown commitment to advancing the rights of children, women, and young people with disabilities by ratifying the UN CRPD, the Convention on the Rights of the Child (UN CRC), and the United Nations Convention on the Elimination of Discrimination against Women (UN CEDAW) (see Table 1). At the national level, Tanzania has domesticated the UN CRPD into the Persons with Disability Act (2010) and the UN CRC into the Law of the Child Act (2019). Tanzania was a forerunner in the East African region in ratifying the UN CRPD and enacting its National Disability Policy in 2004, as the first standalone commitment to the rights of persons with disabilities well before the UN CRPD (Aldersey & Turnbull, 2011; Mitra, 2018). On the African regional and East African sub-regional level, Tanzania is also committed to various human rights instruments that protect the rights of children, women, and yong persons with disabilities.

The key national legislation governing the rights at the intersection of disability, gender, adolescence (the Constitution, the Disability Act and the Law of the Child Act) are not fully compliant with the international frameworks of the UN CRPD, CRC, and CEDAW (Includovate, 2021; UNICEF, 2021). Adolescents with disabilities are hidden in the homogenous image of youth and children, and legislation disregards the unique ways in which female adolescence interacts with disability. The rights of persons with disabilities are non-enforceable as fundamental rights as they are not mentioned in the Constitutional Bill of Rights. Disability is specifically mentioned under the directive principles, but these are not enforceable in a court of law (Section 10(7), Chapter 2) (UNICEF, 2021; Weis, 2017). The domestication of the UN CEDAW remains incomplete, as none of the national laws make specific provisions for women and girls with disabilities (UNICEF, 2021). Furthermore, Tanzania has a poor track record in its reporting on international and regional human rights obligations.

The key regional frameworks approach disability from a medical perspective and disregard environmental barriers. Furthermore, they fail to address barriers that are specific to African or Tanzanian contexts, such as HIV and AIDS, malaria, and material deficits (Oyaro, 2015). Thus, they also fail to capture and build on enablers that are inherently African or Tanzanian, such as the strengths of community living, informal support networks, or communal problem-solving mechanisms.

Table 1 Legal and policy frameworks that govern the rights of adolescent girls with disabilities in Tanzania

Year	**Name**	**Sexual and reproductive health and rights provisions for adolescent girls with disabilities**
International frameworks		
2006	United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)	Sexual and reproductive health is mentioned in Article 25. Human rights to sexual and reproductive health are mentioned throughout the UN CRPD, including under Article 6, which stipulates freedom from exploitation, violence and abuse.
1979	United Nations Convention on the Elimination of Discrimination against Women (UN CEDAW)	Dedicated to protecting and promoting the rights of women. Provisions are not age specific, rendering the unique needs of adolescents invisible.
1989	United Nations Convention on the Rights of the Child (UN CRC)	Seeks to ensure realization of rights of children (under 18), and makes specific mentions of children with disabilities regarding, for instance, the right to life, the right to live a life free from discrimination, and the right to access to education and health care. Makes provisions for the right to a life free from violence for all children.
2015	Agenda 2030 for Sustainable Development	Disability is referenced explicitly throughout the Sustainable Development Goals. Agenda 2030 sets a specific target for universal access to sexual and reproductive health and rights and to eliminate all forms of violence against women and girls under Goals 3 and 5.
1994, 2019	International Conference on Population and Development (ICPD) Programme of Action, and Nairobi Statement, ICPD25+	The ICPD Programme of Action recognizes persons with disabilities as constituting a "significant proportion of the population" and also the needs of persons with disabilities for reproductive health, including family planning and sexual health, information on HIV and AIDS, and education and communication.
Regional frameworks		
1986	African Charter on Human and Peoples' Rights	Article 16 recognizes the right to the highest attainable state of physical and mental health, but does not explicitly mention sexual and reproductive health and rights. Article 18 of the Charter recognizes the rights of persons with disabilities to special measures and treatment. Article 14 recognizes the health of children.
2018	Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (African Disability Protocol)	To date, not yet ratified by the URT. Article 27 explicitly relates to women with disabilities, including girls. It includes the

		dimensions of sexual and reproductive health and rights, such as addressing gender-based violence and bodily autonomy: "the right to retain and control their fertility, and are not sterilized without their consent." Article 28 focuses explicitly on guaranteeing the fundamental rights of children with disabilities.
2003	Protocol on the African Charter on Human and Peoples' Rights of Women in Africa (Maputo Principle)	Article 23 mentions disability in relation to protection from violence and makes provisions for access to economic, professional and educational opportunities on an equal basis with others. It has been described as progressive, especially its reference to abortion and gender-based violence, including harmful practices such as female genital mutilation and child marriage (F. J. Mohamed, 2014).
Sub-regional frameworks		
2012	East African Community Policy on persons with Disabilities	Outlines joint policy commitments in line with the UN CRPD and country-level recommendations.
2016	East African Community Child Policy	Takes an inclusive approach to strengthening the rights of children, also through inter-country partnerships.
2013	East African Community Youth Policy	Sets targets for young persons with disabilities. Approaches disability from a medical perspective.
National frameworks		
1977	The 1977 Constitution of the United Republic of Tanzania	The Bill of Rights stipulates that all human beings are born free, are all equal, and that every person is entitled to recognition and respect for their dignity. Although it does not explicitly mention disability or persons with disabilities, "every" and "all" can be understood to include persons with disabilities. (Section 12).
2010	Persons with Disabilities Act of 2010	Responds to the domestication demands of UN CRPD. Makes provisions for health care, social support, accessibility, rehabilitation, education and vocational training, communication, employment, work protection, and promotion of the basic rights of persons with disabilities. The Act disregards the intersectionality of gender, age and disability and makes no specific provisions for women and girls with disabilities.
2009	The Law of the Child Act	Responds to the domestication demands of the UN CRC. Prohibits discrimination of children based on disability. Applies a medical model to disability, placing an undue burden on individuals rather than the environments that disable them. The Act

		does not recognize the unique forms of disadvantage created by the intersectionality of gender and disability.
2004	National Policy on Disability	First stand-alone policy on disability established already before UN CRPD was ratified. Lacks provisions for accountability and management.
2016	Access to Information Act	Makes provisions on accessibility of the physical environment and information and services for persons with disabilities.
2018	Electronic and Postal Communications Act	Makes provisions on accessibility of information for persons with disabilities.
2003	National Construction Industry Policy	Makes provisions on accessibility of the physical environment.

Health sector policies and strategies apply a highly medicalized model of disability, which highlights the role of the health sector in reducing disability as a way of improving the population's well-being (see Table 2). Moreover, they categorize persons with disabilities, including adolescents with disabilities, as a sub-group of marginalized groups from a demand point of view (i.e., URT, 2018, 2021). Categorizing persons with disabilities, and adolescent females with disabilities, into broad marginalized groups disregards the intersectionality of disability (Stienstra, 2015), and in addition to invisibilizing particular disadvantages, it also hides any advantages to health care access and positive health-related outcomes. Accessibility is acknowledged and highlighted as a key aspect of health care demands and access, also when it comes to sexual and reproductive health and rights.

Table 2 Key national policies and guidance on sexual and reproductive health and rights

Year	**Policy name**	**Content related to adolescence and disability**
2017	The National Health Policy	Endorses adolescents' access to sexual and reproductive health services and addresses inaccessibility as a disability-related barrier to access to services.
2017	Tanzania Development vision 2025	Aims to ensure access to quality reproductive health services for everyone of the *appropriate age* by 2025.
2021	Health Sector Strategic Plan (HSSP V) 2021–2026	Boldy focuses on the principle of *leaving no one behind*. Main objective states that *reducing disabilities* improves the quality of life, depicting a medical model of disability as opposed to a human rights model.
2018	The Adolescent Health and Development Strategy 2018–2022	Adolescents should obtain relevant family planning and STI services. Adolescents with disabilities are mentioned in conjunction with other vulnerable adolescents. Investment in adolescent health is key to preventing disabilities. Depicts a medical model of disability as opposed to a human rights model.
2013	National family planning guidelines	Sets the standard that adolescents, irrespective of their disabilities, have a right to access sexual and reproductive health services that are appropriate for and relevant to their needs.

2016	National Plan of Action to End Violence against Women and Children (NPA-VAWC 2017/2018–2021/2022)	Outlines strategic actions for ending violence against women and children. Does not specifically mention actions targeting the unique forms of violence related to women and girls with disabilities, except in conjunction with vulnerable groups.

The realities of Tanzanian persons with disabilities demonstrate major gaps in the implementation of these policies and legal frameworks. One obvious explanation could be that the accountability mechanisms are insufficient and the policies lack clear implementation frameworks to enforce provision rights (Aldersey, 2012a; Aldersey & Turnbull, 2011; Mapunda et al., 2017). One might also question the appropriateness of international human rights-based frameworks, such as the UN CRPD, for inspiring change in Tanzania when it comes to the rights of persons with disabilities (Abbay, 2015; Onazi, 2020; Oyaro, 2015), the UN CRC when it comes to children with disabilities (Fay, 2019), and the UN CEDAW and the International Conference on Population and Development (ICPD) program of action when it comes to sexual and reproductive health entitlements and freedom from violence for women with disabilities (Oronje et al., 2011; Standing et al., 2011; Undie & Izugbara, 2011).

It has been suggested that the neo-colonial connotations related to the development and human rights apparatus disrupt the existing social and cultural norms and threaten the social well-being of children (Fay, 2019). What further complicates the implementation of such frameworks in Tanzania is also the restrictive-liberal political and social norms divide that characterizes the Tanzanian sexual and reproductive health and rights landscape from service providers to national political discourses (Bylund et al., 2020; Sambaiga et al., 2019).

In sum, despite having made rather comprehensive commitments to the sexual and reproductive health and rights of adolescent females with disabilities, there is a deep disconnect in Tanzania between legal and policy frameworks and lived realities. These formal frames upholding the sexual and reproductive health and rights of adolescent females with disabilities in Tanzania are either constrained by the medicalized view of disability as something to be fixed, by diluting the unique aspects related to the sexual and reproductive health and rights of these adolescents by grouping them together with others in vulnerable groups, or a limited ability to contain aspects pertinent to the Tanzanian context. Moreover, social and cultural norms problematize these frames as a threat to the well-being of the very population whose rights they are meant to uphold. These substantial constraints of the frames, which sustain the sexual and reproductive health and rights of adolescent females with disabilities, call for enriching these frameworks and making Tanzania a highly relevant and intriguing context for research.

The standpoints of adolescent females with disabilities should be better understood if we are to respond to the above-mentioned disconnects. Next, in an attempt to construct an initial frame that could hold the intersection of disability and female adolescence, I describe the theoretical inspirations and conceptual frameworks that were applied in the abductive research process, and which aimed to capture the perceptions of Tanzanian adolescent females with disabilities of their sexual and reproductive health and rights.

3 THEORETICAL INSPIRATIONS AND DEFINITONS OF CONCEPTS

The use of abductive research methodology (Timmermans & Tavory, 2022) led me to problematize the use of some of the theoretical and policy frameworks I had initially planned to apply in this study. I started this research journey with a human rights model of disability and the international policy framework for sexual and reproductive health and rights, but the empirical analysis challenged me to enrich the approach. Thus, what follows is not a presentation of a well-defined theoretical framework; it is more of a description of the theoretical inspirations underpinning my study and the definitions of the central concepts used. Using this approach, this dissertation attempts to counteract the politics of knowledge creation in both disability and development studies that have resulted in the neglect of research on, with, and for persons with disabilities in the global South (Grech, 2011b; Mji et al., 2011; Ned, 2022; Ned et al., 2022; Owusu-Ansah & Mji, 2013). It is based on the claim that local knowledge and disability theorizations originating from the global South have been insufficiently explored and applied (Bezzina, 2018; Grech & Soldatic, 2016; Onazi, 2020; Rao & Kalyanpur, 2020), in particular the intersections of disability, gender, and adolescence (Stienstra, 2015). In addition, scholarly understanding of the alternative framings for sexual and reproductive health, sexuality and the related entitlements that do not take human rights as a starting point is limited; yet such understanding is highly critical.

In this chapter I first introduce disability as a development issue and present the disability theorizations from which this dissertation draws theoretical inspiration. Next, I describe the aspects related to disability that are pertinent to the global South, and thus highly relevant to the Tanzanian research context. I then demonstrate some of the shortcomings of the global North-oriented disability theorizations, and the promising tenets of Afrocentric disability theorizations. After this I proceed to sexual and reproductive health and rights as the international policy framework that I applied as the initial framework for this study. I introduce its development, opportunities and constraints, as well as its key definitions to the reader. Finally, I conceptualize disability in the context of sexual and reproductive health and rights. I conclude the chapter with definitions of adolescence and a discussion on sexual and reproductive health and rights during adolescence.

3.1 Disability and development: Towards an intersectional approach

Disability is an ambiguous, fluid, and complex concept, and its definition varies from one context to another. However, what is common for persons with disabilities worldwide, is that they tend to be among the most marginalized groups in their societies. Their lived realities are often devastating. The social model of disability has transformed the way many societies think about disability (Shakespeare, 2014). The model stems from the 1970s disability movement in the United Kingdom and has been gaining academic prominence through the work of various scholars such as Finkelstein (1980), C. Barnes (1991), and Oliver (1990, 1996). The works of these scholars has counteracted the medical model of disability, which positions disability in the personal realm—as a problem of the individual that needs to be fixed (Oliver, 1990). It refers to an understanding of disability that moves the focus from the individual's impairment to the environment that disables the individual (Finkelstein, 1980; Oliver, 1983, 1986, 1996; Shakespeare, 2020). The social model claims that impairment as such is not disabling, but that disability manifests in the lives of individuals due to the various structural, cultural and social barriers in society, which may be related to attitudes, the physical environment, or communication (C. Barnes, 2020). Whereas impairments are, to a large extent, produced by war, work, or disease (Rembis, 2020), disability can be produced by, for instance, negative attitudes, stairs, heavy snowfall, or insufficient financial means to purchase spectacles (Katsui & Chalklen, 2020).

The social model has been applied in many ways: for example, as a "tool to improve peoples' lives" (Oliver, 2013, p. 1025), as a theoretically grounded basis for emancipatory disability politics, as a way in which to understand the concept of disability (Hughes & Paterson, 1997; Levitt, 2017), and as a foundation to how disability studies should be approached (Shakespeare & Watson, 1997). This dissertation is aligned with the understanding that the strength of the social model lies in the insights it provides on society's relationship with persons with disabilities and on the understanding of disability (Levitt, 2017, p. 590). Despite having changed how disability is understood in many societies, the social model has been criticized for failing to cover the rich, diverse, gendered, and context-bound lives of persons with disabilities (Grech & Soldatic, 2016; Meekosha, 2006; K. Mohamed, 2015; Shakespeare, 2020). This dissertation is aligned with Levitt's (2017) view that "the model's impact on disabled peoples' lives would increase if its emphasis was to more accurately reflect the current social conditions in the geographical regions in which it is applied" (p. 589).

Critics of the social model further claim that the biological and the social are intertwined, and therefore "impairment and disability cannot be easily extracted" (Shakespeare, 2014, p. 22) in the lives of persons with disabilities. Although the binary division of impairment and disability was perhaps needed at the given time in history, to draw attention to the social aspects related to disability, its neglect of disability embodiment resulted in a framework that does not contain experiences related to pain (Przybylo, 2018), internalized oppression (Reeve, 2014) or impairment-specific influences on the experience of disability (Marks, 1999; Rohleder et al., 2019; C. Thomas, 1999). Furthermore, the social model simplifies or disregards the aspects of gender and power dynamics that are at play when multiple marginalized identities intersect (K. Q. Hall, 2011; C. Thomas, 2006; Wendell, 1996). Later on in the history of the social model, the relational understanding of disability built stronger links between the relationships that disable or enable, drawing attention to the positive aspects of relationality in the context of disability (Shakespeare, 2006).

While these have been important developments in the field of disability studies, it was the human rights model of disability (Degener, 2016; Quinn & Degener, 2002) that intertwined disability and development and drew attention to disability beyond the global North. The human rights model of disability is framed by the UN CRPD (2006). The use of this model has rapidly increased around the world (Lawson & Beckett, 2021). The UN CRPD became the first international legally binding instrument to focus specifically on the rights of persons with disabilities, has tremendously changed how disability is understood in international development, and has introduced a new paradigm for disability and human rights (Shakespeare, 2020). According to the UN CRPD, 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"(Article 1, United Nations, 2006). My study leaned on this definition of disability.

The UN CRPD frames the efforts to advance the well-being of persons with disabilities globally. It has been ratified by 186 countries, making it one of the most widely ratified human rights treaties (UN, 2023). Its Article 32 calls for international cooperation; making extraterritorial stipulations for states to support the realization of the rights of one of the most marginalized groups is unique for a convention of this kind (Katsui, 2012; Meekosha, 2011). Its momentum of advancing the globalizing trend of disability inclusion has spread across the world. One impressive achievement of this momentum has been the disability inclusiveness of the global development agenda through the Sustainable Development Goals (SDG) of Agenda 2030. With wide-ranging support from 193 UN Member States, Agenda 2030 was adopted in 2015. It introduced a paradigm shift in the main goal of development, from poverty reduction to reduced inequalities. This shift is visible in what is said to be the cornerstone of Agenda 2030, the "leaving no one behind" principle. Compared to the Millennium Development Goals (MDGs), the Sustainable Development Goals (SDGs) are disability inclusive. Goal 10, "reduced inequalities", and target 10.2 expressly connect the equality of persons with disabilities to sustainable development. Disability is explicitly mentioned in five SDGs and when references to individuals in vulnerable situations are made, there is also a reference that this includes persons with disabilities.

The momentum of advancing the human rights of persons with disabilities is also portrayed through the United Nations Disability Inclusion Strategy, which is the first-ever UN system-wide disability inclusion strategy to have an accountability framework of 15 performance indicators. Each UN agency is annually required to report on these indicators (United Nations, 2019). Additionally, governments situated in the global North have readily adopted the human rights model of disability in their development policies, and it has become the mainstream approach in much of the development sector (e.g., Federal Ministry for Economic Cooperation and Development, 2012; Ministry for Foreign Affairs of Finland, 2016; Sida, 2014b; UK Aid, 2018; United Nations, 2019).

At the nexus of disability and development, intersectionality has recently emerged as a concept and theory that draws attention to the heterogeneity of the lived experiences of persons with disabilities. Intersectionality may be understood as a way in which to respond to the "leaving no one behind" imperative of Agenda 2030, by identifying the structural factors that tend to push certain groups to the margins of society and by targeting focused action on these so-called 'furthest behind groups' through human rights and development initiatives (Baird, Camfield, Haque, et al., 2021). Intersectionality originates from the feminist and critical race theory and was first introduced in the United States by legal scholar Kimberlé Crenshaw (1989). Crenshaw's theorizing centered on illuminating how race intersects with gender and creates unique forms of marginalization and disadvantage. Subsequently, as a theory, praxis, and analytical tool, intersectionality has permeated various fields in the social sciences.

An intersectional approach to disability and development has become a well-established concept in policy and praxis, and is prominent in how inequalities are currently understood (Baird, Camfield, Ghimire, et al., 2021; Collins & Bilge, 2016; Larson et al., 2016; Moodley, 2015). When the multifaceted and nuanced experience of disability becomes difficult to contain in existing frames, intersectionality broadens these frames or creates alternative ones while expanding our understanding of the experience of disability (McCrae, 2019; Moodley, 2015). It does so by contextualizing intersecting identities and stirring reflexivity into the process (Collins & Bilge, 2016; Larson et al., 2016). Recently, intersectionality has been proposed as a viable framework for exploring the marginalization of adolescents in the global South (Baird, Camfield, Ghimire, et al., 2021), as well as in the context of disability (Odeh et al., 2021) and sexual and reproductive health and rights (Coast et al., 2021). This dissertation was motivated by the concept of intersectionality, and I used it to explore the intersectionality of global location, disability, gender, and adolescence beyond the traditional and global North-oriented models of disability.

3.2 Disability and the social model of human rights

The human rights-based approach to development is understood as a conceptual framework to human development that is based on international human rights standards (Sanghera et al., 2015; Stangl et al., 2019; Yamin & Maleche, 2017). According to McGranahan et al. (2021), the human rights-based approach includes ″empowerment of rights-holders and duty-bearers (those responsible for protecting and enacting human rights), non-discrimination, open participation, accountability, and defined and established linkages between rights-holders and duty-bearers″ (p. 2). The principle of non-discrimination specifically supports the empowerment of those in vulnerable positions, for instance, those who are marginalized or discriminated against, to claim their rights and realize their agency (McGranahan et al., 2021; Oronje et al., 2011; Stangl et al., 2019). Moreover, the human rights-based approach necessitates coordinated and multi-sectorial approaches that draw from an analytical understanding of the needs of groups, available resources, and challenges (McGranahan et al., 2021; R. Thomas et al., 2015).

Beyond a mere conceptual framework, the human rights model of disability theorizes disability from a human development perspective, based on international human rights standards. According to Quinn and Arstein-Kerslake (2012) the UN CRPD reconceptualizes what it means to be a human, and provides “the latest iteration of a cosmopolitan theory of justice that happens to be grounded on disability” (p. 38). As regards the paradigm shift, the UN CRPD introduced three key themes that would change how disability is understood (Series, 2020, pp. 80–82). First, the “nothing about us without us”[11] principle, perhaps the most genius political principle of all time, was applied in the drafting of the convention. Persons with disabilities took part in drafting the convention and it became the “landmark achievement of inclusive law-making” (Series, 2020, p. 80). Second, aspects of vulnerability in connection to disability had no room in the convention. This approach constituted a critical change, at least in theory and international policy, in how persons with disabilities are recognized and perceived. In line with this paradigm shift, persons with disabilities would no longer be portrayed as objects of charity but rather as active, self-determining, and autonomous subjects (World Health Organization [WHO] & World Bank, 2011). This was also a move away from the charity-based approach to disability, which used to be prevalent in international development and conceptualizes persons with disabilities as needy and passive objects of aid (Fleischer & Zames, 2011).

Third, the paradigm shift introduced the human rights model of disability. The human rights model of disability addresses the disregard of persons with disabilities by governments, societies, and international development by bringing disability into mainstream development and the human-rights discourse

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[11] This motto entered disability activism in the 1990s and was initially highlighted in disability scholarship and book titles by Charlton (1998) and Werner (1998).

(Katsui & Chalklen, 2020). Quinn and Degener (2002) define the human rights model of disability as follows:

> The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centrestage in all decisions affecting him/her and, most importantly, locates the main "problem" outside the person and in society. The "problem" of disability under this model stems from a lack of responsiveness by the State and civil society to the difference that disability represents. (p. 14)

According to this model, the violation of rights is the cause of disability and the proposed solution is that persons with disabilities, as rights holders, claim their rights and that duty bearers fulfill their responsibilities towards persons with disabilities (Katsui, 2012). While there are distinct differences between the social model and the human rights model, they both claim that the main problem related to disability and human difference is caused by societal factors and not the individual (Lawson & Beckett, 2021) (see also UN CRPD Article 1).

An understanding of the human rights model as an improvement on the social model of disability is prominent in disability studies (Degener, 2017; Lawson & Beckett, 2021); the human rights model represents historic progression from the medical to the social and the human rights models (Degener, 2016). This positions the human rights model as a successor of the social model, and according to the *improvement thesis,* is understood as an alternative to the social model (Degener, 2017; Lawson & Beckett, 2021). In this vein, the social model, with its focus on the social constructs of disability, is criticized for disregarding that disability embodiment is where impairment and disability meet (Owens, 2015). In addition, "the social construct of disability is used not only to **set people apart** but also to **keep people apart**" (Quinn & Degener, 2002, p. 15, original emphasis) because it focuses on the human differences and what societies consider to be normal. Such a focus on difference may not be beneficial for advancing societies that "are genuinely inclusive, societies that value difference and respect the dignity and equality of all human beings regardless of difference" (Quinn & Degener, 2002, p. 15).

Lawson and Beckett (2021) contest this *improvement thesis* with a *complementary thesis*. The relationship between the two models cannot be viewed through the lens of progress, as they have complementary and symbiotic roles, both which work towards removing socially created barriers in order to ensure full respect of the dignity and equal rights of all persons. In working towards the same outcomes, the key difference is that the human rights model is a *model of disability policy*. It guides policy responses to disability by responding to the question "what should be done?" with a blueprint for law and policy and by monitoring progress. The social model, on the other hand, focuses on the concept of disability, which makes it a *model of disability*. According to Lawson and Becket (2021), the strengths of the social model lie in its heuristic nature, which enables discoveries related to disability and social barriers across different contexts:

> The more open-textured social model operates to support emancipatory disability politics in contexts which are not framed by reference to human rights; and continues to be pivotal to the formation, amongst people who have impairments, of a resistant subjectivity based upon shared experience of a disabling society. (p. 371)

These differences between the models' modes of operation underscore the importance of valuing their distinct functions, as they work in a complementary manner (Lawson & Beckett, 2021). In line with the complementary thesis, a social model of human rights has been introduced, which builds on the strengths of the two models (Berghs et al., 2017, 2019). It draws from the perspective that persons with disabilities need "a new stronger social tool for justice, rights and entitlements in society" (Berghs et al., 2019, p. 1037). Although this discussion derives mainly from the United Kingdom, it may also be relevant on a more global scale, as global neoliberal politics have also affected persons with disabilities negatively in the global South, to the extent of leading to mortality and impairment (Berghs et al., 2019).

So, how does the human rights model contribute to enriching the social model? According to Berghs et al. (2019), it has the potential to provide a legislative form of realizing the rights of persons with disabilities beyond a struggle for basic needs. On the other hand, the social model benefits the human rights model with its emancipatory disability politics, or the means to change society and its collective values through political agency and citizenship (Lawson & Beckett, 2021). Therefore, the social model of human rights is a hybrid of the other two models: The social change process ensures dignity and equality for persons with disabilities, the outcome being in the form of realized human rights. Here, I applied the social model of human rights to guide my exploration of the social context of Tanzania without taking the human rights framework for granted. I used this model as a starting point for this dissertation to work towards an enriched disability theorization of sexual and reproductive health and rights.

As demonstrated above, the models and definitions of disability are strongly influenced by historical, research-related, international development, and human rights paradigms which in the case of disability and development are often intertwined. Contextual factors also determine how disability is defined (Kabzems & Chimedza, 2002; Mji et al., 2011; Nyamnjoh et al., 2021; Onazi, 2020). Next, I demonstrate what is unique to disability in the global South contexts and how some aspects pertinent to these contexts challenge the social model of human rights.

3.3 Disability in the global South: Questioning the human rights model

The influential World Report on Disability (WHO & World Bank, 2011) directed the attention of the wider international and development community towards how disability disproportionately affects the global South compared to the global

North. The report's landmark statement that 80 percent of persons with disabilities live in the global South has been utilized extensively to stress the importance of targetingefforts to advance the development and human rights agenda in the global South. I have chosen to use the terms global South and global North in an attempt to show the geographical, social, political, and historical divisions between countries in the Southern and Northern hemispheres. Countries in the global South have traditionally been referred to as "developing" or "The Third World" (Randall, 2004), "post-colonial" (Mbembe, 2001) or "the majority world" (Alam, 2008; Grech, 2011a). They are inhabited by the majority of the world's population and continue to be affected by various forms of coloniality (Grech & Soldatic, 2016; Nour & Connel, 2012). Countries in the global North are generally referred to as "developed", "the minority world" or the "Western, Educated, Industrialised, Rich and Democratic (WEIRD)" countries (Henrich et al., 2010).

Disability in the global South is often portrayed in the global North as a single image of poor and needy individuals who lack agency. This narrative appears to be perpetuated throughout the discourses of the international development and human rights projects directed at the global South (Nguyen, 2016). There is a danger that this narrative will colonize the heterogeneities of the lives of women with disabilities in the global South under a single narrative (Mohanty, 1988; Nguyen, 2016). However, a call for alternative and nuanced narratives of disability, gender, and poverty in Africa is emerging (Peta & Ned, 2019; Shakespeare et al., 2019) with potential to reshape the lives of persons with disabilities (Nguyen, 2016). However, in the process of exploring broader and more nuanced perspectives of disability, caution should be exercised to avoid perpetuating the *supercrip* narrative (McRuer, 2006) or romanticizing the creativity and resilience of individuals, when in fact attention should be paid to the environments in which they live (Shakespeare et al., 2019). Single narratives are also problematic in the sense that they continue to influence the development and application of the concepts of development and disability originating from the global North. These may have far-reaching implications for the well-being and entitlements of persons with disabilities in the global South (Ned et al., 2022). Therefore, "rather than shallow stereotypes, offering the full range of complex stories of real individuals counters this one-dimensional representation"(Shakespeare et al., 2019, p. 6).

Notwithstanding the diverse contexts of the global South, certain characteristics pertinent to them are rather non-existent in the global North. They deeply influence how disability is experienced and construed. Grech (2011b, p. 91) describes these characteristics, which are also highly relevant to Tanzania, as follows: lack of welfare regimes and formal safety nets; strong social ties and close-knit communities; cultural beliefs and ideologies, including religion, which have a strong influence on daily lives and decision-making; diversification of livelihoods consisting of multiple sources that depend on resources subject to the risk of natural disasters and climate change; unreliable or missing markets; households of dual economies engaged in both subsistence and market economies; unequal distribution of land; and a deep urban–rural divide in formal services.

It would be difficult to discuss disability in the context of the global South without addressing the aspect of economic inequalities. As a result of many structural factors, such as barriers to employment, health care and education, and negative attitudes, persons with disabilities in the global South are more likely to experience poverty (Mitra, 2018; Tefera et al., 2018; Trani & Loeb, 2012). The cycle of poverty and disability disproportionately affects women with disabilities, especially those at reproductive age. They have even less educational opportunities, are subject to multiple forms of violence due to their gender and disability, suffer from the impacts of patriarchal ownership structures, and are less likely to be targeted by development programs and interventions (Katsui, 2012; Meekosha, 2006; Moodley, 2015). Furthermore, direct links have been established between economic inequalities and unrealized sexual and reproductive health and rights (Higgins et al., 2022; Melesse et al., 2020; Stark, 2018).

While the UN CRPD has brought about a paradigm change, it has not translated into gains for the majority of persons with disabilities living in Southern contexts (Grech & Soldatic, 2016; Shakespeare, 2014). Despite the UN and other international organizations strongly emphasizing cultural sensitivity (Devlieger, 1999), both human rights ideology and the UN CRPD's narrow, and largely global North-derived perspectives to disability, are increasingly being criticized for disregarding the social, political, economic, and historical aspects of the Southern contexts that affect the majority of the world's persons with disabilities (Abbay, 2015; Grech, 2011b; Grech & Soldatic, 2016; Oyaro, 2015; Rao & Kalyanpur, 2020). Although a participatory approach to drafting the UN CRPD was applied, and a multitude of diverse Southern stakeholders were involved in making the convention (Katsui & Chalklen, 2020), it has been claimed that the global South's representation of persons with disabilities and their representative organizations was insufficient in the shaping of the convention (Lord, 2004) and that topics relevant to, for instance, African contexts were disregarded (Abbay, 2015). This resulted in the neglect of topics that were highly significant in the daily lives of persons with disabilities in the global South, such as sanitation, HIV and AIDS, malaria, and adverse cultural behaviors (Oyaro, 2015). In contrast, the concept of independent living, a topic of less relevance and applicability to the majority of persons with disabilities in the global South, was given specific provisions under Article 19 (Shakespeare, 2020) and has been a highly visible topic in disability rights advocacy.

Furthermore, it has been argued that human rights provide a limited and narrow framework for diverse contexts in which the majority of persons with disabilities live (Katsui & Chalklen, 2020). Global North dominance ignores the lived realities in which persons with disabilities in the global South have to navigate (Connell, 2011; Meekosha, 2011), and persons with disabilities continue to be subjected to both colonial and neo-colonial powers, the latter in the form of development agencies and the human rights project (Bezzina, 2020; Grech, 2015). These agencies implement human rights-based programs designed and formulated in the global North and are often disconnected from the realities of persons with disabilities (Bezzina, 2018, 2020; Grech, 2011b). To start with, rights are not the primary means of understanding well-being and entitlements in many global South settings, making them irrelevant to the individuals and communities in which they are being implemented (Coultas et al., 2020; Standing et al., 2011). Also, rights are generally contested in many African societies and communities (Hameed et al., 2020; Undie & Izugbara, 2011).

The challenges of the human rights frameworks can be elaborated through a disability perspective: First, it has been argued that the individualism embedded in human rights is not relevant or applicable in places where individuals are understood in relation to others (Katsui & Chalklen, 2020; Meekosha & Soldatic, 2011). The human rights framework is seen to neglect the collective perspective of care and social relations which permeate the lives of persons with disabilities in collective cultures (Katsui and Chalklen, 2020). All over the world, families are the source of care and well-being for persons with and without disabilities, but this is even more strongly the case in global South contexts when it comes to disability (Shakespeare, 2020). Furthermore, persons with disabilities in many Southern contexts do not value independence over interdependence, which challenges the autonomous individualism embedded in the human rights frameworks (K. Mohamed, 2015; Shakespeare, 2020). Moreover, the rights-based model often portrays independent living as superior to communal or dependent living (Lovern, 2022).

Second, the universality of rights is seen as neglecting the particularity of rights of persons with disabilities as well as the contextual and cultural understandings of disability and entitlements (Heikkilä et al., 2020; Roodsaz, 2018; Shakespeare, 2020). As human rights are mainly discussed on the international level, they lack engagement with local knowledge and strength-based strategies that have organically developed over time to respond to local needs (Aldersey, 2012b; Harry, 2020; Rao & Kalyanpur, 2020). Moreover, Rao and Kalyanpur (2020, p. 1831) suggest that the universality of frameworks is questionable if there is dissonance between the geopolitical and historical contexts in which the frameworks are constructed and situated. A contextually grounded understanding of disability would therefore better take into account the power relations and different social categories that intersect with disability, such as gender and age (Chiweshe et al., 2017; Macleod, 2018; Nguyen, 2016; Ross, 2018; Stienstra, 2015). These local understandings of disability draw from diverse, contextual understandings of personhood and human difference, and therefore require contextually grounded strategies that human rights-based advocacy and inclusion may not always support (Harry, 2020; Kisanji, 1995; Rao & Kalyanpur, 2020). While human rights have been widely discussed at the international level and tackled on a broad front, engagement in constructive, localized dialogues has been scarce.

Third, it has been argued that the rights-based framework does not sufficiently align or encourage local strengths-based frameworks that are based on local knowledge and have developed over time as a response to local needs, demands, and reasons (Harry, 2020; Kisanji, 1995). Therefore, there is a need to increasingly engage with local knowledge to learn more about the local resources and strategies that benefit persons with disabilities (Rao & Kalyanpur, 2020).

Fourth, binarizing and medicalized understandings of disability in terms of body/mind, abled/disabled, self/other, health/sickness, are not suitable for all global contexts. Such dualistic hierarchies easily reduce persons with disabilities into the position of an inferior (Lovern, 2022). Furthermore, in many contexts, health is understood as living in harmony with others, a view that has gained limited conceptualization in medical scholarship in the global North (K. Mohamed, 2015; Prinsloo, 2001). Thus, concepts that are closely linked to embodiment and disability may need to be understood in more nuanced terms that are not strictly aligned to the human rights-based model (Maybee, 2017; Rohleder et al., 2019; Standing et al., 2011; Undie & Izugbara, 2011).

Fifth, the availability of technical and environmental solutions (and cultural shifts), which the UN CRPD assumes, in the form of, for instance, reasonable accommodations and accessibility measures, have costly implications, especially in contexts grappling with infrastructure and material constraints (Bezzina, 2020; McEwan & Butler, 2007; Visagie et al., 2013). This once more emphasizes the importance of an increased understanding of local strength-based approaches to advancing the worth and well-being of persons with disabilities, which function without external expertise and funding, and are not linked to neoliberal ideologies of effectiveness and efficiency. In development practice, however, the above-described shortcomings of the human rights model are not fully recognized and the model is unquestioned in health (e.g., McGranahan et al., 2021) and disability-related interventions (Bezzina, 2018; Grech, 2011b).

Countries in the global South, including many African countries, continue to be portrayed as peripheral and irrelevant sites of knowledge production, also when it comes to disability research (Grech & Soldatic, 2016; Ned, 2022). When referring to Africa, I acknowledge the diversity of the continent, its societies and communities. Although I try to avoid generalizing where possible, I have decided to use *African* to encompass some of the social, cultural, historical, and philosophical similarities that have been identified in the geographical areas of West Africa, Southern Africa, and Eastern Africa[12]. The exclusion of Africans with disabilities is embedded in colonial histories (MacLachlan & Swartz, 2009) which have resulted in them being treated as an afterthought and being neglected in many areas of daily living in African societies (Ned, 2022). This calls for a "Southern disability theory" (Meekosha, 2011, p. 670), Afrocentric models of disability (Berghs, 2017; Owusu-Ansah & Mji, 2013; Sefotho, 2021) or an African model of disability justice (Onazi, 2020).

Discussion on the Afrocentric models of disability is timely, as the African Renaissance has been recently used to critically reflect on the concept of disability from feminist, historical, and contemporary perspectives as well as to pursue a

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[12] The use of the term "Sub-Saharan Africa" has been discouraged by several African scholars due to its racist undertones and racialist origins. Thus in accordance with Kajula and Chachage (2022), I rely on the compass instead.

higher civilization in which persons with disabilities can be valued as full community members (Ned, 2022; Sesanti, 2016). Additionally, the timeliness of the question "whose lives matter?" has been propelled by the COVID-19 pandemic, which underscored the inequalities produced by disability, gender, and geographical location (Chisale, 2022; Jones et al., 2021; Ned et al., 2020; Shakespeare et al., 2021). *Ubuntu*, an African ethic of interdependence, provides a loose analytical frame in African communitarianism for how human worth is established in relational terms and thus provides a resource for Afrocentric disability models (Berghs, 2017; Ogude & Dyer, 2019; Onazi, 2020; Keikelame & Swartz, 2019). These theoretical resources are recognized throughout this dissertation.

The above discussion calls into question whether or not the term *rights* should be used for conceptualizing and modeling disability. In presenting this critical stance to the human rights framework in the context of the global South, my intention is not to belittle the ultimate aims of this framework, such as dignity and the equal worth of all human beings. Instead, I am trying to contest the strategies and foundations on which these desirable outcomes for humanity are built. Another critical question is whether *rights language* should be applied when discussing sexual and reproductive entitlements in African contexts. The question of conceptualizing disability becomes even more complex when discussed in the context of sexual and reproductive health in the African continent. No alternative policy or theoretical framework originating from the global South has been made available on which to comprehensively frame the discussion on sexual and reproductive health and rights. Thus, while being mindful of the shortcomings of the human rights model described above, I next turn to describing the widely internationally applied policy framework of sexual and reproductive health and rights.

3.4 Sexual and reproductive health and rights from an international development policy perspective

Sexual and reproductive health and rights are understood as essential for sustainable development. Pregnancy and childbirth complications, unintended pregnancies, unsafe abortions, gender-based violence, sexually transmitted infections (STIs), and reproductive cancers compromise the well-being of women, men, and their families (Starrs et al., 2018). To attain the SDGs[13], sexual and reproductive health and rights must also be realized in marginalized and neglected populations. These particular rights are, however, a difficult human rights area, making them some of the most contentious, debated, and politicized rights (Schäferhoff et al., 2019). Subsequently, the advancement of the sexual and reproductive health and rights agenda faces multiple challenges, and millions of people around the world still lack access to a full range of sexual and reproductive

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[13] The reproductive rights of all persons with disabilities and their access to sexual and reproductive health services are explicitly mentioned in SDGs 3.7 and 5.6.

health information, education and services (Starrs et al., 2018). The realization of sexual and reproductive health and rights has been overshadowed by obstacles rooted in sociocultural norms, religious institutions and values, gender inequalities, unfavorable legal and policy environments, and resource and capacity constraints (Buller & Schulte, 2018; Bylund et al., 2020; Chandra-Mouli et al., 2019; Crichton et al., 2006).

The history of sexual and reproductive health and rights in the international arena can be traced back to the 1950s, when the topic of reproduction entered international development politics in the form of population control (Finkle & McIntosh, 2002). The focus of the population control paradigm was not on health or human rights but on fertility control and demographics, and more specifically on securing resources for nation states. The integration of family planning issues into human rights became highly contested and politicized across the secular–religious divide (Berro Pizzarossa, 2018). The women's rights movement concurrently gained momentum and the population control paradigm was criticized in international conferences (Corrêa & Reichmann, 1994; Ross, 2018). In the 1993 World Conference on Human Rights in Vienna, the indivisibility of human rights was highlighted, and reproductive rights became human rights stipulated in international law. This granted women the right to decide on the number, timing, and spacing of their children (Finkle & McIntosh, 2002).

The Programme of Action formulated at the International Conference on Population and Development (ICPD) in 1994 was a turning point for the human rights paradigm in the international population discourse (Berro Pizzarossa, 2018). Family planning was no longer portrayed as a solution to population growth but as a vital tool for empowering women (Starrs et al., 2018). Another significant change was the introduction of sexuality into the discourse of population politics. At the ICPD and the Fourth World Conference on Women in Beijing, China in 1994, the most intense debates focused on whether the term *sexual rights* should be included in consensus documents. This was an intriguing change in the sexual health discourse considering, for instance, African contexts, where sexuality apart from reproduction has often been questioned (Durojaye & Murungi, 2014). Moreover, sexual rights recognized for the first time the sexual health of those who do not necessarily pursue a reproductive role or for whom such a role is often not socially granted. This recognition is especially important for adolescents and in case of the latter, persons with disabilities (Anochie & Ikpeme, 2001; Durojaye & Murungi, 2014; N. Manzini, 2001). Furthermore, the Programme of Action of the ICPD recognized sexual and reproductive health needs and reproductive rights of persons with disabilities. These explicit mentions brought the sexual and reproductive health and rights of persons with disabilities global attention for the first time.

This landmark conference linked the rights of an individual to bodily autonomy to development (United Nations, 2014), as the human rights-based framework for advancing sexual and reproductive health and rights for all was introduced (United Nations, 1995). The ICPD is seen as the peak of the sexual and reproductive health and rights momentum after which an era of fragmentation began (Berro Pizzarossa, 2018). For instance, in 2000, sexual and reproductive health and rights became the watershed aspect for international co-operation to the extent that sexual and reproductive health was omitted from the MDGs as it was feared to jeopardize the Millennium Declaration as a whole (Starrs et al., 2018). It took five years of advocacy and activism to make universal access to reproductive health an MDG target (Berro Pizzarossa, 2018). This was politically important. However, despite some progress, the target itself was not met. To date, the legacy of the ICPD lives on in the development policies and practices in the international realm. For instance, the SDGs have targets that explicitly focus on access to sexual and reproductive health services and reproductive rights for all persons (Targets 3.7 and 5.6).

The definitions of sexual and reproductive health and rights builds on the ICPD and various international and regional agreements and entail four components: reproductive health, sexual health, reproductive rights, and sexual rights (Starrs et al., 2018) (see Table 3).

Table 3 Components of sexual and reproductive health and rights

Reproductive health "A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so." (ICPD Programme of Action) (United Nations, 2014, p. 59).	**Reproductive rights** Reproductive rights are human rights that "rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes their right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents." (United Nations, 2014, p. 60).
Sexual health Sexual health is "a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." (WHO et al., 2017, p. 3)	**Sexual rights** Sexual rights are human rights that recognise the right of everyone to obtain "highest attainable standard of sexual health, seek and receive information about sexuality, receive comprehensive, evidence-based sexuality education, have their bodily integrity respected, choose their sexual partner, decide whether to be sexually active or not, engage in consensual sexual relations, choose whether, when and whom to marry, […] pursue a satisfying, safe and pleasurable sexual life, free from stigma discrimination and make free, informed, and voluntary decisions on their own sexuality, sexual orientation and gender identity." (Starrs et al., 2018, p. 2645).

Starrs et al. (2018) formulated the following integrated definition of the four areas for the Guttmacher-Lancet Commission on Sexual and Reproductive Health and Rights (see Text box 1).

Text box 1 Integrated definition of sexual and reproductive health and rights

Integrated definition of sexual and reproductive health and rights by Guttmacher-Lancet Commission on Sexual and Reproductive Health and Rights (Starrs et al., 2018, p. 2646)

“Sexual and reproductive health is a state of physical, emotional, mental, and social wellbeing in relation to all aspects of sexuality and reproduction, not merely the absence of disease, dysfunction, or infirmity. Therefore, a positive approach to sexuality and reproduction should recognise the part played by pleasurable sexual relationships, trust, and communication in the promotion of self-esteem and overall wellbeing. All individuals have a right to make decisions governing their bodies and to access services that support that right. Achievement of sexual and reproductive health relies on the realisation of sexual and reproductive rights, which are based on the human rights of all individuals to:

- have their bodily integrity, privacy, and personal autonomy respected;
- freely define their own sexuality, including sexual orientation and gender identity and expression;
- decide whether and when to be sexually active;
- choose their sexual partners;
- have safe and pleasurable sexual experiences;
- decide whether, when, and whom to marry;
- decide whether, when, and by what means to have a child or children, and how many children to have;
- have access over their lifetimes to the information, resources, services, and support necessary to achieve all the above, free from discrimination, coercion, exploitation, and violence.”

Furthermore, the definition outlines that sexual and reproductive health services should include:

“• accurate information and counselling on sexual and reproductive health, including evidence-based, comprehensive sexuality education;
- information, counselling, and care related to sexual function and satisfaction;
- prevention, detection, and management of sexual and gender-based violence and coercion;
- a choice of safe and effective contraceptive methods;
- safe and effective antenatal, childbirth, and postnatal care;
- safe and effective abortion services and care;
- prevention, management, and treatment of infertility;
- prevention, detection, and treatment of sexually transmitted infections, including HIV, and of reproductive tract infections; and
- prevention, detection, and treatment of reproductive cancers.”

This integrated definition reflects the emerging international consensus on the services and interventions needed to address the sexual and reproductive health needs of previously neglected groups such as persons with disabilities. I have used this definition of sexual and reproductive health and rights as a policy framework from the outset of this dissertation. Methodologically, this definition provided a loose predetermined frame for participatory agenda-setting. It enabled me to outline, in the following the section, what characterizes the sexual and reproductive health and rights status of persons with disabilities around the world.

3.5 Sexual and reproductive health and rights of persons with disabilities around the world

Despite having the same sexual and reproductive health needs and rights, and despite being as sexually active as their peers, persons with disabilities, especially women and girls with disabilities in the global South, have typically been excluded from accessing sexual and reproductive health and rights (Casebolt, 2020; Hameed et al., 2020; Matin et al., 2021). The COVID-19 pandemic presented new challenges for realizing the sexual and reproductive health of persons with disabilities (Mukherjee et al., 2021).

The UN CRPD, UN CRC and UN CEDAW are the main international legal frameworks that govern the sexual and reproductive health and rights of persons with disabilities. The UN CRPD stipulates governments' obligations concerning the sexual and reproductive health of persons with disabilities. According to Article 25 of the Convention, governments should "provide persons with disabilities with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes." Other references are made in Article 23 (respect for home and the family); Article 16 (freedom from exploitation, violence and abuse); Article 6 (recognition of discrimination against women and girls with disabilities); and Article 21 (access to information). The UN CRC (1989) makes provisions for children with disabilities, and the UN CEDAW (1979) for sexual and reproductive health and rights. The Programme of Action of the ICPD (1994) also recognizes the sexual and reproductive health needs and reproductive rights of persons with disabilities.

Next I describe the barriers and challenges to accessing sexual and reproductive health and rights that many persons with disabilities have to face. To start with, many countries have inadequate national environments, which results in a lack of disability inclusion in sexual and reproductive health and rights (Hanass-Hancock et al., 2021; Mac-Seing et al., 2020; Massay, 2021; WHO, 2022). Furthermore, some laws are discriminatory against persons with disabilities, such as those permitting substituted decision-making (UNFPA, 2018). Disability-focused civil society organizations are often resource-constrained, and find it difficult to access funding (Shakespeare, 2020). As the space for civil society is shrinking in many parts of the world (CIVICUS, 2021), these civil society actors may not be able to hold governments accountable for their obligations to persons with disabilities regarding sexual and reproductive health and rights.

Moreover, false beliefs are widespread that persons with disabilities have few or no sexual rights and do not need as much sexual and reproductive health care as persons without disabilities, are not desirable as sexual partners, and are non-sexual (Casebolt, 2020; Hameed et al., 2020; Hunt et al., 2017; Rohleder et al., 2019; Wilbur et al., 2019). The sexuality of persons with disabilities is generally considered a taboo subject (Carew et al., 2017). Stigmatization begins early, and is shaped by social and cultural negative and dismissive attitudes (McKenzie, 2013; Mckenzie & Swartz, 2011) then perpetuated by communities, educators and health care providers (Bangura et al., 2021; Hunt et al., 2017; Meer & Combrinck, 2015; Sanga et al., 2022). Relatives, teachers, and health care providers are often anxious, untrained, and unconfident about discussing sexuality with young persons with disabilities (Ballan, 2012; Sanga et al., 2022; Tugut et al., 2016). Stigma is particularly strong concerning persons with intellectual and psychosocial disabilities (UN Special Rapporteur on the rights of persons with disabilities, 2017). Other stereotypes include false beliefs that girls and young women with disabilities are suitable for exploitation and abuse (Bangura et al., 2021; Njelesani, 2018), and are unable to manage their fertility or raise children (Dean, 2017; Devkota et al., 2019; Gartrell et al., 2017). These beliefs have far-reaching impacts on the lives of women and girls with disabilities in areas such as education, and on their access to information and services that could enable them to enjoy safe and healthy sexual lives (Nampewo, 2017; Valentine et al., 2019; Wallace et al., 2018). Furthermore, there are significant gender gaps among adolescents with disabilities. Twelve percent of boys and 21 percent of girls report having felt discriminated against or harassed within the last 12 months on the basis of disability (UNICEF, 2021).

Because persons with disabilities are often perceived as not needing information on sexual and reproductive health and rights or as incapable of making decisions about their sexual and reproductive lives, persons with disabilities are often unaware of their sexual and reproductive health and rights or how to claim them (Carew et al., 2017). It is well established that youth with disabilities, especially young persons with intellectual disabilities, have poor knowledge about sexual and reproductive health and rights, also about the prevention and transmission of HIV (Isler et al., 2009; Kahonde & McKenzie, 2019; Kassa et al., 2016). This can lead to risky sexual behaviors, such as low levels of condom and contraceptive use and HIV testing (Aderemi et al., 2014; Mprah, 2013). Accessible sexuality education that addresses disability-specific needs is often unavailable (Bastable et al., 2020; Sanga et al., 2022). Stigma and stereotypes concerning sexuality can also lead to the exclusion of persons with disabilities from any existing sexuality education programs (Mall & Swartz, 2014). There is a general lack of guidance on how to talk about sexuality and equality with children and youths with disabilities (Sanga et al., 2022; UN Special Rapporteur on the rights of persons with disabilities, 2017).

Persons with disabilities are often not allowed to make decisions about their bodies, health, or sexuality (Björnsdóttir et al., 2017; Patel, 2017). For instance, girls and young women with disabilities are disproportionately affected by gender-based violence (Chisale, 2022; Meer & Combrinck, 2015; Namatovu et al., 2018; Njelesani, 2018). Acts of violence often happen during daily activities such as dressing or toileting, or when receiving treatment. Sometimes these girls and young women are even overmedicated (UNFPA, 2018). Gender-based violence occurs in public and private spaces such as homes, schools and health facilities, and the perpetrators are often those on whom the girl depends, such as family members and caregivers (Meer & Combrinck, 2015; Namatovu et al., 2018; UN Special Rapporteur on the rights of persons with disabilities, 2017). Forced sterilization disproportionately affects girls and young women with disabilities (Björnsdóttir et al., 2017; Patel, 2017), at even three times higher rates than the general population (UN Special Rapporteur on the rights of persons with disabilities, 2017). Those with intellectual disabilities in particular are more likely to be subjected to forced sterilization (Tilley et al., 2012). Many legal systems still allow others to give consent to sterilization on the basis of their perceived best interests of the person with disabilities.[14] Women and girls with disabilities often experience pressure to end pregnancies due to misconceptions about poor parenting and eugenics (Devkota et al., 2019; Potvin et al., 2019). Forced contraception is also often used to control menstruation (Quint, 2014; van Schrojenstein Lantman-de Valk et al., 2011).

The negative attitudes discussed above deter many persons with disabilities from seeking sexual and reproductive health care. Compounding this, the sexual and reproductive health facilities in many global South settings are physically inaccessible, lack adaptations such as ramps or transferrable equipment, and frequently have long waiting lists (Casebolt, 2020). Even if the services are made physically accessible, barriers to accessible communication and information remain (Mills, 2020; Mprah, 2013; Rugoho & Maphosa, 2020). The distance of health care facilities are also a barrier for many, especially when transportation is often inaccessible, unreliable, and expensive (Casebolt, 2020). Many require escorts to their health appointments, which increases costs and jeopardizes confidentiality (Burke et al., 2017). Health care professionals often share socially entrenched negative attitudes towards disability and sexuality (Casebolt, 2020; Pebdani et al., 2014). Low levels of knowledge about disability across the medical profession lead to attitudinal barriers in health care services (Burke et al., 2017; Tugut et al., 2016).

After this overview of sexual and reproductive health and rights from the perspective of disability, I now present the definition of adolescence and the unique aspects related to it in the context of sexual and reproductive health and rights.

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[14] E.g., the concluding observations of the Committee on the Rights of Persons with Disabilities in relation to the reports of Argentina, Australia, Brazil, Canada, Chile, Colombia, China, the Dominican Republic, El Salvador, Jordan, Kenya, Lithuania, Mongolia, New Zealand, Peru, Portugal, Qatar, the Republic of Korea, the Republic of Moldova, Serbia, Slovakia, Spain, Thailand, Turkmenistan, Ukraine, Uruguay, and the European Union.

3.6 Adolescents' sexual and reproductive health and rights

Adolescence is typically understood as the growth and development between childhood and adulthood (Baird, Camfield, Haque, et al., 2021; Furlong et al., 2011; Patton et al., 2016; Villa-Torres & Svanemyr, 2015). It is a phase of biological changes and social transformations that can determine the trajectory of a person's life (Buller & Schulte, 2018; J. L. Morris & Rushwan, 2015; Patton et al., 2016; Viner et al., 2015; WHO, 2014). Many adversities push children directly into adulthood, without allowing them to experience adolescence or youth as a season of preparation, experimentation, and transition (White & Wyn, 1996). Many of these adversities are related to unrealized sexual and reproductive health and rights such as unwanted pregnancies, early marriages, and gender-based violence (Patton et al., 2016; Starrs et al., 2018).

This dissertation acknowledges that age-related benchmarks are not universal and may be different for different population groups in different contexts (Furlong et al., 2011; Villa-Torres & Svanemyr, 2015). For the purpose of this research, however, age provides a useful frame of reference for understanding the transitions from childhood to adulthood. Adolescence has policy-related and programmatic implications, and thus a global definition of adolescence has been developed that facilitates statistical consistency and comparisons across countries. According to WHO, adolescents are individuals aged 10–19 (WHO, 2014). The majority of adolescents are covered by the definition of *child* adopted by the UN CRC, that is, a person under the age of 18, but some adolescents also fall under the category of young people (aged 10–24). The category of adolescence has been widely utilized in relation to sexual and reproductive health and rights, as some of the aspects of sexual and reproductive health related to adolescence are unique.

The foundation for a healthy sexual and reproductive life is laid during adolescence (Patton et al., 2016). Sexual activity, cohabitation, married life, and early childbearing shape and increase the needs for sexual and reproductive health services and information of this population (Starrs et al., 2018). Moreover, adolescent sexual and reproductive health and rights are highly gendered. Despite positive trends in adolescent sexual and reproductive health, almost 30 years after the ICPD, adolescent girls in the global South are disproportionately affected by negative health outcomes (Chandra-Mouli et al., 2019). For instance, half of the pregnancies of adolescent women aged 15–19 in the global South are unintended, and of the 252 million adolescent girls living in the global South, an estimated 38 million are sexually active (Darroch et al., 2016).

It is not catastrophizing to say that sexual and reproductive health and rights are a matter of life and death for adolescent girls in the African continent (Durojaye, 2009; Massay, 2021; Patton et al., 2009). For instance, adolescent girls are the demographic with the most new HIV infections in Africa (UNAIDS, 2022). Unsafe abortions also contribute significantly to the maternal deaths of adolescent girls in Africa (Bankole et al., 2020), also in Tanzania (Woog & Pembe, 2013).

Moreover, the first sexual experience of adolescent girls in Africa is often violent (Moore et al., 2007). Inequalities in sexual and reproductive health and rights remain great among those further marginalized. For example, adolescent births are concentrated among those on the outermost margins of society (Melesse et al., 2020; Neal et al., 2020).

The concepts of childhood, adolescence, youth, and adulthood have blurred borders that are influenced by contextual power dynamics (White & Wyn, 1996). These dynamics respond to individuals differently according to, for example, their global location, gender, disability, HIV status, ethnicity, and migration status. The ambiguousness of adolescence has implications for policy and practice. In spite of the urgent need to advance adolescent sexual and reproductive health and rights being well acknowledged among sexual and reproductive health researchers, health practitioners and activists, adolescent sexual and reproductive health and rights are often low on the list of international and local priorities, at the bottom of foreign policy agendas (Buller & Schulte, 2018), and invisibilized in the SDGs (Guglielmi & Jones, 2019).

3.7 Chapter summary

In this chapter, I have explained the theoretical inspirations and definitions underpinning this dissertation. I began by introducing disability as a development issue, alongside the disability theorizations and policy frameworks behind this undertaking. I presented the social model of disability and the human rights model of disability. These models are embedded into the definition of disability applied in this dissertation, which outlines disability as the result of interaction between an impairment and an environment that places persons with disabilities in an unequal position in comparison with others. I also introduced the concept of intersectionality as an inspiration for this study in the quest to expand the frames that hold the experiences of persons with disabilities, especially adolescent females with disabilities, in Southern contexts. Drawing on some of the unique aspects of the lives of persons with disabilities in Southern contexts, I critiqued the human rights model, a conceptual framework for human development that is based on international human rights standards, for its inability to inspire social change in global South contexts. Notions of neocolonialism such as individualism, universalism and neoliberalism in particular, seem ill-fitted to the Southern contexts in which the majority of persons with disabilities live. In response to these shortcomings, I introduced the potential of Afrocentricity for reconsidering disability theorizations. Despite these promising models, I concluded that the Afrocentric disability theorizations have still not provided a comprehensive framework for sexual and reproductive health or their related entitlements, and so I turned to the international policy framework on sexual and reproductive health and rights. Using this framework, I described the sexual and reproductive health and rights of persons with disabilities. Finally, to explore the intersection of disability and adolescence, I introduced the concept of adolescence. I define it here as a period of social and biological transformation between the ages of 10 and 19, which has a significant impact on well-being and sexual and reproductive health and rights across an individual's entire lifespan.

How then can one move beyond global North dominance when it comes to the conceptualizations and understandings of disability, adolescence, and sexual and reproductive health and rights? For the interests of this dissertation—the context of Tanzania, disability, and female adolescence—what would it require to establish a framework that has the capacity to hold the richness of intersectional identities and experiences that are embedded in the collectivist worldview as opposed to an individualized one without taking for granted the disputed nature of sexual and reproductive health and rights? According to Rau and Kalyanpur (2020, p. 1845), the empirical studies currently emerging from the global South, as well as the postcolonial literature, indicate two ways of addressing the shortcomings of recognizing, valuing and building on the contextual and localized knowledge and practices related to disability. The primary focus should be on the epistemic standpoints and experiences of people in local contexts (also in Bezzina, 20,18; Tlostanova & Mignolo, 2012), and then it should turn to the available strengths and resources related to the local conceptualizations of disability and disability-related practices (also in Aldersey, 2012b; Harry, 2020). Based on this view, in order to enrich the narrow conceptualizations of disability and adolescence and to explore the collective resources related to sexual and reproductive health and rights within the Tanzanian context, it is now essential to delve into the perspectives of Tanzanian adolescent females with disabilities. Next comes a description of the methodology that I applied to capture these perspectives.

4 RESEARCH METHODOLOGY

The sexual and reproductive health and rights of persons with disabilities are a stigmatized topic around the world (Amin et al., 2020), to the extent that even persons with disabilities themselves often feel uncomfortable when sexual matters are discussed in association with disability (Mall & Swartz, 2014). The scarcity of research on this topic results from the politicized and disputed nature of these particular rights and their cultural and contextual sensitivity, as well as the particularities related to conducting research with persons with disabilities (Amin et al., 2020). Methodological and ethical challenges are often more intense when research is conducted with adolescents with disabilities in contexts in which they are seldom encouraged to express themselves (Pincock & Jones, 2020; Wickenden & Kembhavi-Tam, 2014). Failure to capture the views of adolescents with disabilities has various implications for the inclusion of the aspects specific to their sexual and reproductive health and rights in research, policies and practices (Trani et al., 2011). Furthermore, the scarcity of studies on this topic also suggests that the experience and evidence of the methodological developments in sexual and reproductive health and rights research with adolescents with disabilities is limited. Below I describe the research methodology I have used in my attempt to fill these gaps and to explore the standpoints of Tanzanian adolescent females with disabilities: I used qualitative abductive methodology as an avenue to enriching existing theories.

4.1 Qualitative abductive methodology

This dissertation is grounded in the social constructivist paradigm and aims to understand the social world of the study participants (Denzin & Lincoln, 2018). In my quest for rich exploratory data, and in an attempt to explore the perspectives and social worlds of adolescent females with disabilities in the Tanzanian context, I used qualitative methodology (Denzin & Lincoln, 2018).

When conducting my research on the sexual and reproductive health of adolescent females with disabilities in Tanzania, I moved in a largely unmapped terrain. The topic remains undertheorized in Tanzania and similar contexts, meaning that there were few theoretical frameworks from which to draw for research of this kind. Due to this scarcity, and as I was motivated to make room for alternative framings beyond the narrow conceptualizations based on theories originating from the global North on disability and the human rights framework, I chose to draw from qualitative abductive inquiry (Timmermans & Tavory, 2012).

The abductive approach makes it possible to combine inductive and deductive reasoning. This in turn enables existing theoretical and conceptual frameworks to be recognized and combined with the observed phenomena (Awuzie & McDermott, 2017) in a systematic manner (Timmermans & Tavory, 2012). Abduction places observational surprises at the center of qualitative research design (Timmermans & Tavory, 2012). The following steps of the abductive inquiry model (Oh, 2008) were critical to the abductive research process in order to enrich the existing theories. Next I describe the steps of *exploration*, *examination*, *selection*, and *explanation*.

In the *exploration phase*, inductive reasoning is incited (Given, 2008). The groundwork is laid for the following phases, in which whether what is being observed might be explained by a currently existing theory or whether new theoretical contributions are needed is determined (Oh, 2008; Ponelis, 2015; Stebbins, 2001). In this phase, the researcher observes an empirical puzzle (Adler & Adler, 2009) and seeks to understand it better. For instance, I investigated the studied phenomena using the data I collected, which resulted in discoveries regarding the role of relationships, the value placed on interdependence, and the entitlements that flow from belonging.

The *examination phase* recognizes that although abduction “starts from the empirical findings it does not deny the role of prior theoretical knowledge in providing explanations” (Lukka & Modell, 2010, p. 467). During this phase, I needed to activate and expand my knowledge to identify the rules and logic that could explain what I encountered in the data. It was only when I read about the African communitarian philosophy that these empirical puzzles started to make sense. What followed was the *selection phase*, which included making comparisons and evaluating the different disability models in an attempt to find the most plausible explanation for the empirical phenomena (Conaty, 2021). In the *explanation phase*, the enriching of theories depends on the researcher’s ability to stimulate creative ideas about innovative theoretical contributions on the basis of the data (Timmermans & Tavory, 2012). Thus, during this phase, I revisited the exploration phase by returning to the contextual empirical material and its puzzles, aiming to explain it through the new theoretical ideas.

The roles of the researcher, theory, method, and data are central in the abductive process and are used to justify employing abductive inquiry in this research (Timmermans & Tavory, 2012). First, abductive methodology enabled the researcher’s experience to be recognized and harnessed to enhance the research (Conaty, 2021), as it placed positionality at the heart of the methodology

(Timmermans & Tavory, 2012). The ability to recognize that a finding is surprising sets parameters for what is being looked for. It relies on expertise and familiarity with theories (Thompson, 2022; Timmermans & Tavory, 2012) and, I would add, familiarity with the context from which the empirical material has been collected. My prior experiences and being immersed with the field had made me aware of the complex social realities in which adolescent females with disabilities navigate and the disputed nature of sexual and reproductive health and rights in Tanzania. I was able to manage and recognize this prior experience and immersion through the abductive research process and by fostering reflexivity (Conaty, 2021).

Second, the abductive approach provides room to decide whether an initial theoretical frame may or may not be applied (Conaty, 2021). In this research, the studied phenomena required advancing theories and concepts in a largely uncharted theoretical landscape. The previous chapter presented the theoretical and conceptual inspirations of the empirical study, based on the unique fieldwork I had conducted in Tanzania over a period of five years, during 2018–2022. The timeline is presented in Table 4. Third, participatory research (see Section 4.2) resonates with abduction as a methodological approach as it supports a sustained, in-depth interaction between the researcher and the empirical context (Conaty, 2021). The methodological choices thus enabled me to revisit the phenomena, defamiliarize the known world, and apply alternative framings (Timmermans & Tavory, 2012, pp. 175–179) through the different streams of knowledge that the participatory process made available.

Fourth, this process involved revisiting data through repetitive methodological processes (Timmermans & Tavory, 2012). Data was positioned "against different theories such that data can contribute to and develop further the chosen research questions" (Ahrens & Chapman, 2006, p. 820). This repetitive process allowed the data to work to its strengths by moving from what may have been initially perceived as relevant or interesting framing, such as sexual and reproductive health and rights violations, to examining the underlying factors against the cultural and social fabric that enable and constrain the flow of entitlements and establish worth.

Table 4 Timeline of the research

	2018	2019	2020	2021	2022
1–3	Conducting literature review	Setting the research agenda within the predetermined frame of sexual and reproductive health and rights Developing and contextualizing the empathy-based story method Conducting the pilot study	Data collection (Articles I and II) Data analysis (Articles I and II)	Publishing Article I Discussing preliminary results with research advisory committee (Article II)	Publishing Article III Validating results with research advisory committee (Article II)

4–6	Submitting research plan Recruiting research assistant	Revising methodology on basis of pilot study Data collection (Articles I, II and II)	Data analysis (Articles I and II) Discussing preliminary results of analysis with research advisory committee (Articles I and III)		Planning dissemination of findings Submitting Article II for publication
7–9	Formalizing collaboration with SHIVYAWATA Obtaining research permit	Data analysis (Article III)	Data analysis (Article II)		Planning dissemination of findings
10–12	Obtaining ethical clearance Establishing research advisory committee	Data analysis (Article III) Preliminary data analysis (Articles I and II)	Validating results with research advisory committee (Article I and III)	Planning dissemination of findings Beginning dissemination of findings	Review of Article II in
11 research advisory committee meetings were held. The dissemination of the research results continues beyond this timeline in collaboration with SHIVYWATA.					

4.2 Participatory disability research

The methodology of the study drew on participatory disability research (C. Barnes, 2003; Buettgen et al., 2012; Katsui & Koistinen, 2008). Development studies have seen participatory research as a move away from external expertise in order to value the local expertise and knowledge possessed by the most marginalized in particular (Cooke & Kothari, 2001). In the field of disability studies, the participatory research paradigm became prominent when the shift from a medicalized model of disability to the social model of disability took place and participation became one of the central claims of the international disability movement (Katsui, 2012). Critical and decolonial disability studies claim that the created knowledge on disability should yield justice for persons with disabilities (Minich, 2016) and center their voices (Mietola et al., 2017; Ned et al., 2022; Owusu-Ansah & Mji, 2013). This dissertation did not deliberately set out to apply the emancipatory research approach, but the potentiality of challenging discriminatory structures and the power imbalances nevertheless served as motivation for this research and its methodology. The level of power given to the research participants is not, however, equal to that of the researcher; an issue that distinguishes participatory research from emancipatory research (C. Barnes et al., 1999; Katsui, 2012; Katsui & Chalklen, 2020; Walmsley, 2001). Therefore, although some elements of the research process and outcomes are emancipatory by nature and challenge the current social order, the research confines itself to a participatory approach, acknowledging the issues of power, as will be discussed later in this chapter in Section 4.9.

In this dissertation, participatory research is understood as an exploration of "relevant issues for persons with disabilities in the form of partnership with persons with disabilities" (Katsui, 2012, p. 45). When studying persons with disabilities, there is a danger that their participation may be cosmetic or tokenistic with no active role in the research (Walmsley & Johnson, 2003). In my attempt to avoid this critical failure, the participatory research design was based on a research triad consisting of the researcher, a Tanzanian research advisory committee and a Tanzanian research assistant with disabilities.

The research advisory committee was established in collaboration with SHIVYAWATA, which consists of 10 member organizations of persons with disabilities.[15] The cross-disability committee consisted of 11 members (n=11), six females (n=6), and five males (n=5), and a male Tanzanian research assistant with physical disabilities was also employed[16] (n=1). Two females had physical disabilities (n=2), one was a deaf person (n=1), one had partial vision (n=1), one had blindness (n=1), and one had albinism (n=1). Three males had physical disabilities (n=3), one had albinism (n=1), and one was deaf (n=1). Despite various attempts to employ a female researcher with disabilities I was not successful, even through SHIVYWATA's networks. The fact that the expertise required for a study of this kind was unavailable may reflect the status of women with disabilities in Tanzania in general.

At the beginning of the study, the terms of collaboration were negotiated with the research advisory committee. The voluntary nature of this study was emphasized, and confidentiality was discussed and agreed to in writing. Furthermore, the committee members were ensured that they would be compensated for the time they invested in the research. They received a payment of 8 euros[17] per meeting, which was negotiated with them. Meetings usually lasted 6–7 hours on selected Saturdays, and tea and lunch were always served. We held 11 committee meetings, which lasted from 4 to 8.5 hours. The research advisory committee members were not familiar with online meeting platforms and did not all possess the technology needed to conduct such meetings. Therefore, the COVID-19 pandemic interrupted the participatory process, reducing the number of meetings to

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[15] Tanzania Albino Society (TAS), Tanzania League of the Blind (TLB), Tanzania Association of the Physically Handicap (CHAWATA), Tanzania Association of the Deaf (CHAVITA), Tanzania Association of the Deaf–Blind (TASODEB), Tanzania Association for the Mentally Handicap (Inert), Kilimanjaro Association of Spinal cord Injuries (KASI), Psoriasis Association of Tanzania (PSORATA), Tanzania Users and Survivors of Psychiatric Organization (TUSPO), Association of Spinal Bifida And Hydrocephalous of Tanzania (ASBAHT)

[16] While person-first language, in line with the UN CRPD, is also becoming mainstream in Tanzania, not all disability groups in Tanzania choose to use person-first language, such as the deaf. As words can be used to further stigmatize persons with disabilities, I decided to respect the views of the research advisory committee members from different disability groups, even when it was decided first to use a person 'with impairments' and then later on "with disabilities". This summary uses "with disabilities" as opposed to the "with impairments" used in the research articles.

[17] To provide a relative sense of the amount, 8 euros enables a person to travel 440 km by public transport, for instance from Tanga to Arusha. A proper lunch with a drink in the city center costs approximately 1.8 euros.

two in 2020, and one in 2021. Critical reflections on compensation and the burden of this research to the committee members and participants are discussed in Section 4.7.

Including persons with different disabilities in research advisory committees is known to increase the diversity of views and address power imbalances between different disability groups (Kuper et al., 2021). Having a cross-disability research advisory committee was an attempt to ensure that persons with disabilities maintained an active position throughout the research, which was crucial for setting a relevant research agenda within the predetermined loose research frame of sexual and reproductive health and rights, developing appropriate methods, interpreting the data, validating the results (Caretta & Pérez, 2019), and disseminating the findings (Kuper et al., 2021). In addition, triangulating the data that was produced through the empathy-based stories and the research advisory committee proceedings enhanced in-depth interpretation and reduced researcher bias. Reducing researcher bias was possible through, for instance, triangulating the concepts that emerged from the data—such as *utu*, the Swahili term for humanness or full social inclusion—and multilayered cultural understandings of the community and informal support networks. In addition, without the research advisory committee, I would not have had access to such experiential, political, and cultural streams of knowledge (Sanderson et al., 2013).

The specification of the research agenda involved first presenting the sexual and reproductive health and rights framework to the research advisory committee (see integrated definition of sexual and reproductive health and rights). Next, a series of discussions, ranking and participatory exercises were conducted to understand which areas within this loose framework were relevant to the context of adolescence, disability, and Tanzania, based on expert perspectives. The topics were then narrowed down, according to consensus, to access to services, violence, and menstrual health. These topics were then selected as the themes of the three stand-alone sub-studies and subsequently the three articles through which the results were to be published.

4.2.1 Dissemination of newly generated knowledge

Participatory disability research requires newly created knowledge to be disseminated in ways that are accessible to the research participants (Katsui & Chalklen, 2020; Kuper et al., 2021). We used conventional academic practices, such as journal and newspaper articles, publications, presentations in academic conferences, university lectures, and stakeholder discussions on sexual and reproductive health and rights and disability rights in the international development fora in Tanzania. However, the participatory research approach required going beyond these conventional means. Targeted action was taken which would ensure that the knowledge that was created would also reach and potentially benefit the study participants, the research advisory committee members, and Tanzanian adolescent females with disabilities. This is still ongoing. It includes translating the research findings into Kiswahili and ensuring that the information is also accessible to different groups of persons with disabilities. We co-produced the research findings into *Easy Read* formats to popularize them and reach larger audiences in Tanzania, including those with intellectual disabilities (see Figure 1. Audio, Braille print, and large print versions of these continue to be published, and the dissemination of these knowledge products has a funding plan in collaboration with SHIVYAWATA and international non-governmental organizations.

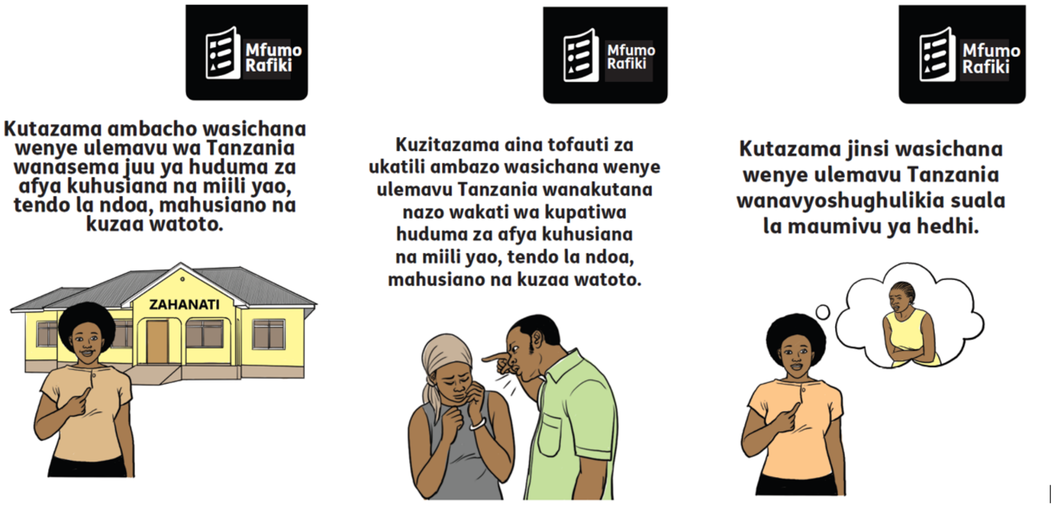

Figure 1 Cover pages of the three Easy Read documents presenting the study results

Persons with disabilities continue and will continue to be engaged in the dissemination efforts during events organized to commemorate the International Day of Persons with Disabilities, the Day of the African Child, and the International Women's Day, for example. Furthermore, knowledge has been disseminated as a part of global and national advocacy campaigns such as 16 Days of Activism against gender-based violence. Through such events, our knowledge has reached and continues to reach various groups of persons with disabilities, policy-makers, and international development agencies thanks to SHIVYWATA's central role as representative of the Tanzanian organizations of persons with disabilities to the government and other stakeholders. Due to adolescent sexual and reproductive health and rights being such a disputed topic, it was decided that in order to ensure the safety and confidentiality of our adolescent participants, they were not directly involved in the targeted dissemination efforts.

This targeted dissemination has been carefully planned and it would be important to analyze its significance and successes, especially the use of the Easy Read format, which was new to the Tanzanian context and the stakeholders of the study. Such rigorous analysis is a key suggestion for further research.

4.3 Participants and study sites

Purposive sampling (Given, 2008) was used to identify the participants from a sampling frame established together with the research advisory committee. This provided strategic opportunities to engage the participants with the most potential to deepen our understanding of the studied topic. The sampling frame criterion was chosen to include participants with diverse disabilities from the 10-to 19-year age group. The research advisory committee were involved in determining the sampling frame and suggesting study locations. The final decisions, however, were made by the researcher and the research assistant by prioritizing access and diverse representation. Using personal connections to gatekeepers such as community leaders and headmasters has been identified as a useful recruitment method for building participants' trust in disability research in African settings (Grischow et al., 2021). The final selection of locations was not communicated to the research advisory committee to ensure the confidentiality of the study participants.

The participants in the studies for Articles I and II consisted of 136 female Tanzanian adolescents with disabilities, aged 10 to 19 (see Table 5). The average age of the participants was 15.5 years. The majority were deaf persons (n = 42); one also had a physical disability. Others were persons with physical disabilities (n = 33) and albinism (n = 32), and some of these were had partial vision (n = 11). In addition, some participants had intellectual disabilities (n = 13), blindness (n = 12), and partial vision (n = 4). The research was conducted in 13 locations across three regions in mainland Tanzania, mostly in school settings. Other settings included youth and community centers.

The study results published in Article III concerned 63 Tanzanian females with disabilities, aged 12 to 24. The majority had physical disabilities (n=43) whereas the rest had intellectual disabilities (n=6), partial vision (n=3), were deaf persons (n=3), or had albinism (n=2), dwarfism (n=1) and a heart disease (n=1). One participant had both an intellectual disability and a physical disability (n=1) and the type of disability of three participants remained unknown (n=3). Data was collected in two locations in two regions in Mainland Tanzania. It mainly consisted of data generated in school settings. In addition to these study participants, representatives of organizations of persons with disabilities in Tanzania (n=7) also took part in the research. They were from organizations of persons with spine and spinal cord injuries, psoriasis, intellectual disabilities, and deafblindness. Additionally, one expert represented the viewpoint of the menstrual health management of persons with disabilities. The roles of these experts gave them knowledge of the status of females with disabilities beyond their own experiences, making them insightful sources of information.

Table 5 Study participants

	Article I and II	Article III
Number of participants	136	63
Age	10–19	12–24*
n=Deaf	42 (including one with physical disabilities also (n=1))	3
n=Physical disabilities	33	45 (including one with dwarfism (n=1) and one with a heart disease(n=1))
N=Albinism	32 (including one with partial vision also (n=1))	2
n=Intellectual disabilities	13	7 (including one with physical disabilities also (n=1))
n=Blindness	12	
n= Partial vision	4	3
Unknown disability		3

* 4 participants were over the age of 19 (which places them in the category of young people, according to the UN definition). As the majority fell within the definition of adolescents, I use this term throughout this dissertation.

4.4 Method of empathy-based stories

The art of storytelling has been applauded as a powerful tool for conveying information in various African contexts. This is also the case in Tanzania, where storytelling is a method of communal knowledge generation that does not exclude children (Seehawer, 2018; Traore, 2010). Storytelling is a collaborative process of meaning-making and while individual contributions are important to storytelling, this is only the case in connection to the community, its past, present, and future (Mucina, 2011; Seehawer, 2018). A story can maintain cultural continuity, aim for cultural change, or enable a culture to regenerate (Imbo, 2002; Seehawer, 2018). Storytelling from this perspective is a deeply participatory and interactive process in which the audience responds to the prompts of the storyteller until the storyteller is convinced that the audience and the storyteller are synchronized (Mucina, 2011). Furthermore, storytelling has proven to provide participants from various backgrounds and of different ages with a voice, allowing them to contribute to the discussion on given topics (Posti-Ahokas, 2013; Särkelä & Suoranta, 2020; Sinkkonen et al., 2017) and regarding them as competent experts of their culture (Wallin, Koro-Ljungberg & Eskola, 2019).

This dissertation employs the *method of empathy-based stories*. The method is based on constructivist epistemologies, and assumes that reality is contextually and socially constructed (Eskola, 1997; Eskola et al., 2017). The first three decades of the method of empathy-based stories has demonstrated that this methodological curiosity has become an established research method, also internationally (Wallin et al., 2015). It is employed to acquire the perspectives rooted in the participants' narratives, and assumes that reality and the narrative reflect and imitate each other and that the ability of the narratives to reflect personal meanings is more important than capturing lived experiences (Wallin et al., 2018). Therefore, the focus of the method of empathy-based stories is not on investigating the participants' experiences, but their perceptions. Nevertheless, it does allow participants to disclose their lived experiences if they so wish.

For research of this kind, which focuses on some of the most intimate spheres of human existence, ethical considerations influence the method selection. The method of empathy-based stories is considered an ethically sensitive data collection method, as it allows participants to distance themselves from potentially distressing topics (Wallin et al., 2018). *Empathy-based stories* are fictional short stories narrated by the study participants as a response to *frame stories* provided by the researcher (Eskola, 1997; Posti-Ahokas, 2013). The frame stories for this dissertation, as well as the visual and audio aids accompanying them, were developed with the research advisory committee and piloted prior to the data collection. Due to their unique characteristics, as well as their educational status, the participants took part in the storytelling orally or in writing. The oral storytelling sessions resembled individual interviews, in which the participants first responded to the frame story. After this, predetermined prompt questions provided more insights into the participants' views (See Annex 1 for the story session guide).

The frame stories for Articles I and II were constructed around two protagonists: Fatuma and Nuru. The stories reflected two common issues that lead adolescent females to seek sexual and reproductive health services in Tanzania—teenage pregnancy and STIs (Mbeba et al., 2012), and simulated perceptions of the accessibility and inaccessibility of these health services. Data collection was conducted in Kiswahili, as it was the lingua franca of the study context, in cooperation with a native Kiswahili-speaking research assistant, as well as in Tanzanian sign language, with the support of a Tanzanian sign language interpreter. The frame stories were as follows:

> 1.1 Fatuma John is an 18-year-old girl with disabilities and she is pregnant. She needs to attend the health clinic. After visiting the clinic, she feels happy and safe. Tell us what happened at the clinic that made her feel happy.
>
> 1.2 Nuru Hassan is a 15-year-old girl with disabilities. Nuru has a disease in her private parts and she is experiencing discomfort. She needs to see the doctor. In the meeting with the health professional something goes terribly wrong. Afterwards Nuru is really upset. Tell us what happened when she met the health professional. Tell us what disturbed her so much.

For Article III, two different frame stories were used during data collection, both consisting of a positive and a negative version. The topics addressed by the frame stories were performance of daily activities during menstruation and self-perception caused by different perspectives on menstruation. The versions for Frame story 1 were as follows:

> 2.1 This story is about a teenage girl with a disability. The girl is menstruating, and she performs her daily activities as usual. Empathize with the girl and explain what makes her able to perform her daily activities, such as family life-related tasks, education, and social activities as usual while menstruating.
>
> 2.2 This story is about a teenage girl with a disability. The girl is menstruating, and she is not able to perform her daily activities. Empathize with the girl and explain what makes her unable to perform her daily activities, such as family life-related tasks, education, and social activities, while menstruating.
>
> The following versions were used for Frame story 2:
>
> 3.1 This story is about a teenage girl with a disability. The girl is told that menstruation is a completely natural and normal process in a woman's life. Empathize with the girl and explain how this perception of menstruation affects how she sees herself as a young woman.
>
> 3.2 This story is about a teenage girl with a disability. The girl is told that menstruation is shameful, dirty, and disgusting. Empathize with the girl and explain how this perception of menstruation affects how she sees herself as a young woman.

The frame stories were open-ended, which invited a sense of familiarity with stories that are typically non-conclusive and reflect the position of the storyteller (Mucina, 2011). Thus, the method of empathy-based stories also enabled decentralizing the role of the researcher, as the use of a story method was not ambiguous and did not require expert knowledge. Integrating predetermined prompts made the interaction between the researcher and the participants structured and systematic. Orality enabled an additional layer of collectivism that cannot be achieved through written accounts, as written stories lack interaction. According to Achebe (1988), when stories are written, collective ownership is lost: "The story told by the fireside does not belong to the storyteller once he has let it out of his mouth. But the story, composed by […] the writer in his study, 'belongs' to its composer. (p. 47)"

4.4.1 Methodological responses to study contexts and research topic

The frame stories are central to the success of the method of empathy-based stories, therefore the frame stories were contextualized to ensure access to and capturing the perceptions of the studied adolescents. The original form of the method required adjustments based on the Tanzanian context to make sure that it responded to the characteristics of the studied adolescents, and thus, the frame stories were carefully constructed around local elements, names, locations, and objects. The formulation of the frame stories with the research advisory committee was an interactive and iterative process in which story drafts were circulated from individual group members to the group and through the pilot study back to the research advisory committee. This also created a sense of ownership of the stories and the research process among the research advisory committee members.

Based on the contexts and study topic, the three most radical changes to the original application of the method of empathy-based stories were the following. Although usually, empathy-based stories are produced in writing, in this study the story sessions employed orality and resembled interviews. This enabled the participants to join in the storytelling orally or in writing, according to their unique characteristics. The frame story initiated the oral storytelling, and the prompt questions were used to increase engagement in the stories and to gain a deeper understanding of the topic. Oral storytelling traditions have a strong foothold in children's Swahili culture, and still continue to inspire storytelling (Bertoncini, 1989; Goldman, 2011; Ohly, 1985; Traore, 2010). This increased the familiarity of the story method for the participants. It also allowed me to integrate prompt questions that entailed elements of typical Swahili stories such as the use of didactic entertainment for children and youth (Ohly, 1985; VanWormer et al., 2018). It provided an opportunity for the participants to give advice to the protagonists and reflect on the lessons to be learnt. Second, all the participants were given the opportunity to respond to both frame stories. It would have been ethically questionable if some participants had only been able to respond to the negative version of the frame story (see Posti-Ahokas, 2013).

Children's actions are regulated by a range of social and cultural norms (Christensen and O'Brien 2003) and many of these norms are visible in school settings, which were the main sites of data collection. In the Tanzanian context, schools are typically places of both protection and punishment, safety and danger (Fay 2018). In recognition of and in an attempt to address this, it was emphasized to the participants that the storytelling was not a school assignment, there were no right or wrong answers, and there would be no punishment for not completing the story. Overall, the storytelling created a space that aligned with the norms of the communal knowledge generation. The following explains not only the adjustments made to the method of empathy-based stories related to context and study sites, but also the disability-related accommodations.

4.4.2 Responding to the characteristics of the studied adolescents

This dissertation study deliberately sought to include adolescent females with different disability types to counteract the disability hierarchies related to knowledge production (Scully, 2020). This required disability-specific accommodations in recruitment, in the informed consent processes, and in the data collection techniques. I adhered to the ideas of Wickenden and Kembhavi-Tam (2014), that in cross-disability research it is beneficial to group the participants according to their capabilities. Visual and audio aids were developed to help the participants understand the stories used in the studies for Articles I and II . The visual aids are presented below (see Figure 1 and Figure 2). I ensured that the participants with blindness and partial vision and/or physical disabilities had physical accessibility. Deaf participants and/or those using alternative means of communication were provided with sign language interpretation and/or visual story aids. Those with intellectual disabilities were provided with visual story aids, and the pace was adjusted and repetitions were used. In general, the participants' education level was taken into account, and the style of language and length of sentences were adjusted. Overall, the visual accommodations seemed to be useful to most participants, except for those with blindness, who instead received an audio story aid. The support provided by the audio and visual story applications increased the participants' engagement in comparison to that in the pilot study when these were not provided.

Figure 2 Visual aid for Fatuma's story

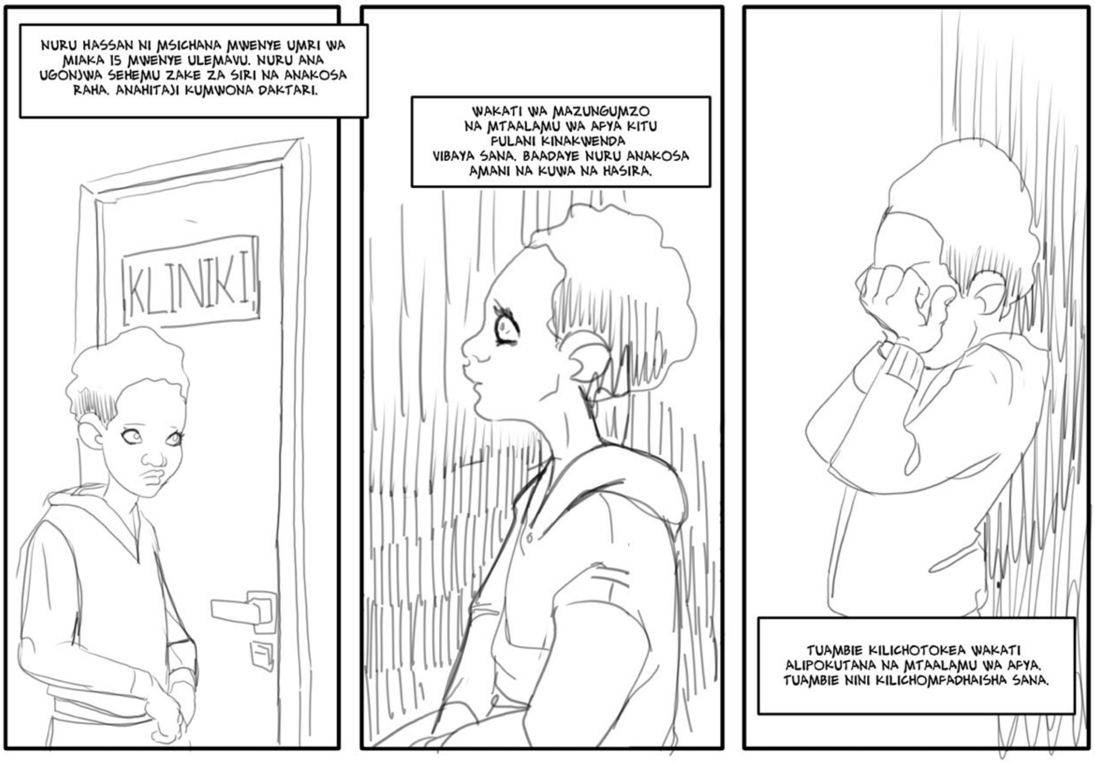

Figure 3 Visual aid for Nuru's story

The participants with blindness were very attentive listeners of the audio version of the frame story. Their facial expressions and bodily movements portrayed excitement at hearing a young female voice on the recorder, and this may have incited their imagination about the protagonist. The participants with albinism were a unique group. They were reluctant to storytelling and answering the prompt questions. Repeating the frame story and using prompt questions were common techniques in the story sessions with them. This group also showed anxiety about their stories and sometimes gave different answers to the same interview prompts when asked again. They often responded "I don't know" and their responses were brief.

> The suspicious looks they gave when I talked to them… I realized that maybe this came from their home or the communities around them. Due to the killings of persons with albinism, they were perhaps identified as vulnerable and dependent on others' protection. […] I decided to discuss this with the research advisory committee. One of the members told me: "They are afraid of everyone they talk to, often [at home] they are told to be careful so that no-one will harm them."
>
> Research Journal, April 16, 2019

The deaf participants who used Tanzanian signs in the storytelling were the most enthusiastic storytellers. Professional Tanzanian sign language interpreters were present in their story sessions. The common characteristic of this group was that they were willing to share what they knew about the topic, and to explain it thoroughly and in great detail. "It was as if they had no secrets", the research assistant commented after data collection from the deaf participants. It appeared that they had a wealth of understanding of sexual and reproductive health issues and were willing to share when this platform was made available to them.

The participants with intellectual disabilities produced very little audible data but this did not mean they had little to say. We mostly observed their facial expressions and body language for discomfort, or their familiarity with a certain story element. Their expressions were documented in research notes, and I interpreted the documentations together with the research assistant. The experience of using the method of empathy-based stories with them was generally positive, but my ability to respond to their characteristics and their rich emotional narratives was somewhat limited.

Despite the positive responses to storytelling, cultural norms (Lalwani et al., 2006), social status (Johnson & Van de Vijver, 2003), and gender (C. A. Kelly et al., 2013) may have made the participants align their stories with what is perceived as socially acceptable to share through stories. Next, I explain how I limited the social desirability tendencies in this research.

4.4.3 Addressing social desirability tendencies

Social desirability tendencies are more common in research on issues that participants find sensitive or controversial (Grimm, 2010). Research on sexual and reproductive health and rights in African settings show that there is a tendency to adjust the message according to what the speaker thinks that the listener will approve (Bergen & Labonté, 2020). Thus, I turned my attention to ways in which I could limit social desirability bias, such as focusing on method design, as described above, and adjusting the interviewer's interpersonal characteristics to the research setting (Krumpal, 2013).

According to the method of empathy-based stories, data is usually collected in writing, which reduces the social desirability bias (Wallin et al., 2018). However, our data was mostly orally collected, so we lacked this benefit. To ensure the reliability of the data, I had to remain methodologically responsive to the characteristics of the studied adolescents, and thus had to limit social desirability through other means. Building trust and increasing the comfort and ease of the participants has shown to limit the social desirability bias and increase the validity of data (Bergen & Labonté, 2020; Krumpal, 2013). Humor has been acknowledged as a disruptive element that can lead to spaces of free self-expression (Mayo, 2010). During the informed consent procedures and the storytelling sessions, the research assistant and I, the researcher, attempted to build the participants' trust by using humor and self-disclosure and displaying respect by, for instance, emphasizing participants importance for this research. The research assistant described the use of humor as a technique to deduce social desirability tendencies as follows: "I would say: 'Look at me, I'm not a teacher! I don't even carry a stick, so nothing's obligatory here!' And this would make them [the participants] laugh."

Bergen and Labonté (2020, p. 787) have suggested other techniques that can be used to minimize social desirability bias, and I found these useful in this research. First, indirect questioning in the form of taking the perspective of the protagonist is at the heart of the method of empathy-based stories. Not having to respond on one's own behalf may have reduced the social desirability bias of the participants. In a similar vein, allowing the data collection to reflect the simplicity, ease and fun of storytelling counteracted the unfamiliarity of Western research practices and the complexities of using the school as a research setting that could have reinforced social desirability tendencies. In the following, the research assistant describes the benefits of the method in relation to the increased freedom of expression in the school space: "If you are asked questions, you feel interrogated. But reading a story [frame story] together, that's something else. You don't need to feel like you're being confronted or have to know the answers". Second, providing assurances, such as reminding participants that the research is not schoolwork was important. Third, we created an interview guide including prompt questions to probe more information. Fourth, prefacing questions by, for example, reminding the participants about the protagonist of the frame story was effective: "Remember the main character in the story, she's a girl with disabilities."

4.4.4 Pilot study

Pilot studies are important for determining any weaknesses or risks related to methods and are thus encouraged in qualitative methodology (Kim, 2011). During the spring of 2019, the methods and consent procedures were tested on a group of 20 adolescent females with disabilities and their guardians. The findings of the pilot study suggested that the *bureaucratisation of ethics* (N. Morris, 2015) may take its toll on the research and research participants in the Tanzanian settings, as written contracts contradict traditional practices of trustworthiness and orality (Ahimbisibwe et al., 2021; Araali, 2011; Grischow et al., 2021). The participants and their guardians considered the consent procedure ambiguous, s they did not understand the purpose of the paperwork. Furthermore, I was left feeling uneasy not only about the amount of the documentation perplexing participants but also the level of the "informed" consent. In an attempt to address the latter, we decided to include an explain back protocol in the consent procedure to address this issue in the following research phases. The dilemma of the cultural characteristics of the study locations and adhering to the international principles of ethical research with consent and assent forms was resolved by giving the caregivers and participants an improved explanation of why the paperwork was needed, and then proceeding with the requirements of international ethical standards.

Challenges related to the socially and culturally sensitive topic of the study also arose during the consent procedure of the pilot study. After our explanation of the research aims, and after providing the information letter, we observed that the guardians became increasingly unsettled and started whispering to each other. Finally, one of them stood up and delivered the question they had collectively pondered: “So you want to bring men here to teach our daughters how to have sex?”. This question clearly revealed the shortcomings of the way in which we had conveyed the information about the research. Thus, we revised the consent material and the consent process to respond to the characteristics of the guardians, who had never been exposed to the Western research code of conduct or education. More importantly, however, the guardians’ concerns were highly relevant and revealed an important element related to access negotiations.

During the piloting of the method of empathy-based stories, we observed that the participants were not initially very engaged in the stories, which adversely affected their willingness and enthusiasm to become storytellers. To encourage stronger engagement, the method was adjusted: Predetermined prompt questions were added to compliment the frame stories, and audio and visual applications were developed. Furthermore, as the stories were initially observed as too complex and long, they were further simplified, and the protagonists were given names that could better ignite the participants’ imagination and familiarity with the research topic. These elements seemed to increase their engagement in the storytelling and provided more in-depth insights into their views in comparison to the pilot study and subsequent data collection.

It had also been initially planned that some secondary data would be collected in health facilities delivering sexual and reproductive health services. However, the pilot phase revealed that long waiting periods made the interviews with hospital staff extremely time-consuming. Furthermore, the hospital staff were careful not to say anything potentially controversial, as the policies and political discourse on sexual and reproductive health and rights are often perceived as contradictory, as further described in Bylund et al. (2020). The social desirability biases left me with trivial information, thus the interviews with the health care staff were not included in the final research design. Instead, efforts and resources focused on elevating the voices of the adolescents themselves. Furthermore, we noted that the focus group method was not applicable to adolescent females with disabilities in this study. Due to the cross-disability nature of the study, it was difficult to conduct a discussion with participants if multiple disability-related accommodations were simultaneously in place. As the activity would exceed the allocated time of 1.5 hours, it was decided that the method of empathy-based stories would be the main method of data collection.

4.5 Data

The data for Articles I and II drew from 257 empathy-based stories that were on average 902 characters long and were produced by the 136 participants. The data for Article III was collected by each participant responding to a randomly designated version of both frame stories. This resulted in 27–35 stories for each story version, a sufficient quantity for analysis purposes (Eskola, 1997). Hand-written stories were collected from 44 participants who felt confident about expressing themselves fluently in writing. Nineteen participants with intellectual disabilities, more severe physical disabilities, and sensory disabilities told their stories orally. The participants who wrote their stories had up to an hour to do this, and the time used for writing varied from 20 minutes to one hour, whereas the duration of the oral story recordings varied from 14 to 35 minutes, conforming to each participant. The orally collected stories were transcribed verbatim by the research assistant immediately after the interviews. The transcripts and the written stories were translated from Kiswahili into English and crosschecked by a member of the research advisory committee and the researcher to ensure the quality of the data.

In addition to the data generated through the empathy-based stories, various legal and policy documents were reviewed to establish a comprehensive picture of the governing frameworks of persons with disabilities in Tanzania. This complemented the dissertation as a form of secondary data. Focus group discussions are often used as a method to generate and explore issues in a social context (Breen, 2006). The research advisory committee meetings resembled focus group discussions, and on selected occasions when the preliminary results were discussed and the final results validated, the group discussions had a predetermined agenda and were recorded, transcribed, translated, and mainly used for the triangulation of the findings. Some of the extracts from these discussions are used to center the voices of the research advisory committee members in the concluding chapter. During other discussions in the advisory committee meetings, notetaking was the main form of keeping records of discussions. Moreover, for Article III, seven semi-structured interviews (Denzin & Lincoln, 2018; Fontana & Frey, 2008) of female leaders of the disability movement in Tanzania were utilized to contextualize the interface of menstruation and disability. In addition, reflexive accounts based on the experiences and observations of the author and the research assistant were documented in a research journal (35 pages) and three reflexive discussions were recorded (7.5 hours in total). Some of the extracts from the reflexive discussions and research journal are used to demonstrate aspects related to researcher reflexivity and power in this and the following chapters.

Management and handling data is an important aspect in ensuring the success of a research project, data security and safety, and the confidentiality of the study participants. Immediately after data collection, all the recorded data was transcribed, and the written data as well as any other documentation were transformed into digital versions, after which these files were stored behind a password with strict access by the author only. All the data was then carefully anonymized before translation. The files were named systematically and consistently and transferred to the data management and analysis software Atlas.TI on a secure server. All hard copies were then destroyed. Data handling agreements were made with the research assistant and the translators, who were trained on the principles of managing and handling data.

4.6 Methods of data analysis

According to Timmermans and Tavory (2022), abductive analysis means doing qualitative research differently. For instance, “abductive analysis means designing research explicitly to maximize the chances of data surprises; engaging the literature in a different way; approaching data coding with a mindset of defamiliarizing the familiar; and writing research up deliberatively and reflexively to evoke abductive insights” (p.4). Although abductive analysis may be inspired by existing conceptual or theoretical frameworks, it does not attempt to fit findings into them; it leaves room for conceptual and theoretical contributions (Flick, 2017). Thus, we used the current understanding of sexual and reproductive health and rights and disability in relation to the three different research topics: access to sexual and reproductive services, gender-based violence, and menstrual health. Then, the unexplored epistemic standpoints of adolescent females with disabilities were used to challenge these topics to reach a more comprehensive understanding of them (Kennedy & Thornberg, 2018). I also used thematic analysis (Braun & Clarke, 2006; Nowell et al., 2017), with some aspects of quantitative content analysis (Coe & Scacco, 2017) for Articles II and III. Both methods have been acknowledged to align well with the method of empathy-based stories (Särkelä & Suoranta, 2020) and are especially used for identifying, analyzing and reporting patterns within data (Braun & Clarke, 2006). The initial analytic focus was on the meaningful aspects in the data that responded to the research questions (Chenail, 2015).

In Atlas.TI, I first divided the data into smaller shares by the frame story versions then tagged the empathy-based stories based on the storytellers’ age group (older or younger adolescent), disability type, and anonymized study location, to find the differences between the groups or locations. For the analysis conducted for Article I, I first found the notions of access and lack of access by separating the story versions. Then I freely coded recurrent patterns and topics. Being theoretically sensitized, in accordance with the abductive approach (Timmermans & Tavory, 2022), the codes began to resemble dimensions of access in the Levesque model of health care access (Levesque et al., 2013), in which the ability of services to respond to the characteristics of persons with disabilities was embedded (also in Casebolt, 2020). The appropriateness of the dimensions was discussed with the research advisory committee, as were the proposed codes under each dimension. Based on this triangulation of the data analysis results with the research advisory committee, the thematic locations of the codes were refined and thematized under the Levesque model’s dimensions of access (Levesque et al., 2013).

When I started work on Article II, I was already very familiar with the data, as it was the same as that used for Article I. A theme that had emerged during the previous analysis phase was violence when accessing sexual and reproductive health services. During the setting of the agenda with the advisory committee, violence against adolescent girls with disabilities was selected as one of the main topics to be researched, and due to the scarcity of studies in this area, we decided to look at violence in the context of access to services in the second publication. The appropriateness of the themes that emerged from the data was again discussed with the research advisory committee until a consensus was reached on the following: forms of gender-based violence when accessing sexual and reproductive health services, inaccessible and inappropriate communication, and the collective dynamics of accessibility and protection. Quantitative content analysis (Coe & Scacco, 2017) was used in the sense that the appearances of certain types of violence were quantified and reported in the findings in this order, from the most common to the least common.

For Article III, thematic analysis was used to examine the data. The process was data-driven, as during data analysis, it emerged that menstrual pain was distinctly one of the main factors that deterred the daily activities of young women during menstruation. Quantitative content analysis determined that pain was mentioned in 41 percent of the stories, being the most common denominator across menstrual perceptions and the most frequent way to describe perspectives on menstruation. The contents of the stories were coded, focusing on any narratives mentioning pain. The codes were categorized into themes according to the social relational model of disability (Reeve, 2019; C. Thomas, 1999); disablism, psycho-emotional disablism, impairment effects, and psycho-emotional impairment effects. This categorization again utilized the theoretical sensitization of the researchers. Due to the context- and disability-related accommodations made to the method, the impact of story variations was not observed during analysis; the empathy-based stories were analyzed as one entity, beyond the division created by the story variations.

Despite the engagement of the research advisory committee, co-authors, and the research assistant, and their important inputs into the thematic analysis, I remained in the driver's seat, and made the decisions during the course of the analysis[18]. Indeed, in qualitative research, the researcher becomes the most important analytical instrument (Peredaryenko & Krauss, 2015). To ensure the trustworthiness and credibility of the data analysis process, despite it being in the hands of a sole researcher, the following steps were followed. First, *triangulation exercises,* which meant triangulating the data between the co-authors and the research assistant; triangulating the methods, including the focus group discussions and interviews; and the investigators including the research assistant as a co-researcher (Denzin, 1970; Rothbauer, 2008). Second, *prolonged engagement with the context and participants* was applied as a strategy to facilitate thorough data collection and field work (Keikelame & Swartz, 2019). Third, *transparency* was established by an audit trail of the records (Ryan-Nicholls & Will, 2009) consisting of data transcripts, field and meeting notes, evaluation exercises for the research advisory committee, data analysis process descriptions, and a chronological draft of the interpretation of the findings. Fourth, fostering *researcher reflexivity* (Guillemin & Gillam, 2004; Keikelame & Swartz, 2019) is an essential step of

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[18] For Article III, the data was co-analyzed with the second author Magdaleena Lehmuskoski.

rigorous qualitative research as it reduces researcher bias. This was done through journaling and reflexive discussions with the researcher assistant (see more on researcher reflexivity and positionality in Section 4.9). Table 6 summarizes the methodology of this dissertation.

Table 6 Methodological summary

Article	I*	II*	III
Aim	To understand the inequalities faced by adolescent females with disabilities when accessing sexual and reproductive health services	To investigate the contextualized links between access to sexual and reproductive health services and gender-based violence	To explore disability embodiment and sexual and reproductive health and rights inequalities through the lens of menstrual pain
Sampling	Purposive sampling frame established with the research advisory committee	Purposive sampling frame established with the research advisory committee	Purposive sampling frame established with the research advisory committee
Participants**	136 adolescent females with disabilities 10–19 years old	136 adolescent females with disabilities 10–19 years old	63 young females with disabilities 12–24 years old
Context	13 locations across three regions in mainland Tanzania, mainly school settings	13 locations across three regions in mainland Tanzania, mainly school settings	2 locations in two regions in Mainland Tanzania, mainly school settings
Methods	Method of empathy-based stories Focus Group Discussions with research advisory committee	Method of empathy-based stories Focus Group Discussions with research advisory committee	Method of empathy-based stories Semi-structured interviews Focus Group Discussions with research advisory committee
Data	257 empathy-based stories, on average 902 characters long when transcribed Hand-written stories Audio-recorded stories 2 Focus Group Discussions	257 empathy-based stories, on average 902 characters long when transcribed Hand-written stories Audio-recorded stories 2 Focus Group Discussions	126 empathy-based stories, 27–35 stories for each story version Hand-written stories Audio-recorded stories 7 semi-structured interviews 2 Focus Group Discussions

Analysis	Abductive approach, thematic analysis	Abductive approach, thematic analysis, some elements of quantitative content analysis	Abductive approach, thematic analysis, some elements of quantitative content analysis

* For the studies conducted for Articles I and II, the same data set was utilized

** For the study conducted for Article III, 7 expert interviews were conducted for contextualization. Participants included 7 representatives of Organizations of Persons with Disabilities in Tanzania. The was no overlap with the participants of Studies I and II.

4.7 Research ethics

Given the sensitive nature of this research, ethical considerations have informed this dissertation. First, I describe the ethical principles that were fundamental for this research and how they were shown in the research practice. Then, I discuss how the ethics affected my methodological choices. After this, I present how we adhered to the international ethical standards, namely informed consent, confidentiality, and participant safety. Then I describe compensation, and what we did to minimize the burden of this research for the participants.

The ethical foundations of this research were informed by two core ethical values that stem from the understanding that all human beings have inalienable worth: *mutual respect* and *epistemic modesty* (Kittay, 2010). For *mutual respect*, I contemplated issues of power and control in great depth, especially with regard to the researcher and the research participants. More profoundly, related to epistemological and methodological considerations such as theories, concepts and methods, I reflected on the systems of oppression that may be perpetuated through this research, such as coloniality. According to Kittay (ibid.), *epistemic modesty* means the kind of humility that enables me to accept and recognize my limitations as a researcher in my level of understanding of the research participants and the social worlds I will be able to generate. I allowed *ethically important moments* (Guillemin and Gillam 2004), understood as "disruptions from the expected course of data collection" (Robinson, 2020, p. 1), to distract my research work, and unveil my own normative and ableist assumptions. Such revelations led me to question: Is voice a voice even if it does not fit the frames of conventional research practice? For instance, my understanding of what is useful data changed in the course of this research. Despite careful planning and preparation to respond to the characteristics of adolescent females with intellectual disabilities, I encountered my own limitations as a researcher to sufficiently include non-spoken and non-linear voices in this research. Although both I and the research triad lacked the expertise to comprehend and interpret the majority of these rich and valuable narratives, the fact that they were included in the study and that observations were made on their contributions aligns with the ethical understanding on the inalienable worth of all human beings.

I also considered ethical aspects when making methodological choices, by applying an abductive reasoning that allowed me to move beyond the theorizations of the global North. Participatory disability research was established with the research triad to address the privilege and power of the researcher (Katsui & Koistinen, 2008; Mayoux, 2008; Thapar-Bjorkert & Henry, 2004). The method of empathy-based stories was chosen as an ethically sensitive data collection method as it allows participants to distance themselves from potentially stressful topics. It was selected as a way to minimize any potential psychological stress that the research may cause. Efforts were made to create safe research spaces that would ensure and promote physical and psychological safety as well as freedom of expression (see discussion on safe research spaces in Section 6.5.2). Furthermore, I carefully considered the accessibility of the locations, methods and materials to elevate the diverse voices (van der Heijden et al., 2019).

I adhered to the ethical code of conduct that provides a rather typical and global North-oriented approach to research ethics, although at times I questioned the suitability of such protocol in the Tanzanian setting, especially concerning the aspects of orality, illiteracy, trust, and conviviality, which are almost the antithesis to the paperwork and agreements that characterize global North research ethics. Research clearance[19] was obtained from the Tanzania Commission for Science and Technology and ethical clearance[20] from the Ethical Review Board of the National Institute of Medical Research (NIMR), which was renewed annually. I also applied for permission to publish from the NIMR. This two-fold documentation, together with the agreement of collaboration with SHIVYAWATA was also required by the regional and district offices, and for school administration or village leaders to obtain official permission for data collection.

The guardians and adolescents were invited to information sessions in which the information sheets were read and explained to them. The combined information sheet and consent form (Annex 2 and 3) was formulated to provide the caregivers with information about the research and its aims. The information sheet and the assent form (Annex 4 and 5) provided to the adolescents contained the same information but used simpler language. The information sheets were also provided in large print, and braille versions were made available. They included information on the researcher, the purpose of the study, the reason for participation, the benefits and risks of the research, data handling and management, and the importance of parent consent and adolescent assent. The sheet also contained the contact number and email address of the researcher. This information was provided in case any concerns or questions regarding the research arose afterwards.

To ensure that the consent was indeed informed, there was a section in the assent form on the talk-back protocol, which asked the adolescent to answer simple questions about the research, in accordance with the talk-back protocol (Talevski et al., 2020; Tamariz et al., 2013). This was to ensure that the participants

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[19] Research permit No. 2018-455-MFS-2018-161

[20] Ethical clearance reference NIMR/HQ/R.8a/Vol. IX/2970

established an understanding of the research. The talk-back protocol was repeated in a conversational manner until it was determined that the participant had a sufficient understanding of the research, and understood that taking part in the research was voluntary. The participants were reminded at the beginning of their storytelling sessions about the voluntary nature of the study and the right to withdraw from it at any time. The confidentiality and privacy of the participants was prioritized throughout the research process. Their identities were hidden in the data, and careful anonymization ensured that the stories could not be connected to the storytellers. The study regions and locations were not disclosed to even the research advisory committee. However, the participants in the study sites knew each other as fellow students, and this somewhat limited the confidentiality of their participation in the research. I adhered to the "do no harm" principle to the best of my ability, but as no follow-up mechanism was established, it is impossible to trace any negative consequences that this research may have had in the lives of the participants.

I came to the conclusion that, due to the unique characteristics of the context and the participants, the formalized research procedures described above were not sufficient with marginalized adolescents. Therefore, ethics were understood more broadly, as situational and responsive, in line with Morrow (2008). I applied consent as an ongoing process (Cowie & Khoo, 2017), by observing the positive responses of most of the participants to the invitation to express their perspectives in this research.

The participants' reactions to the data collection sessions were enthusiastic. This showed that they perceived the research as interesting and relevant as they seemed excited about becoming storytellers. A small number withdrew from the study during data collection—their reasons were usually practical and not related to the study topics. I observed gaps in many participants' knowledge about sexual and reproductive health and rights as they expressed a desire to ask many questions about them.

Being responsive to how participants expressed their ongoing consent required continuous monitoring of both their explicit and implicit signs of ease and comfort. Considering the potentialities of the power distance between the participants and the researcher, I had to be observant of any signs of reluctance or discomfort.

> *This one participant didn't say anything, so we went back to the story and then she turned her face quickly towards me and it seemed as if she was enjoying it as she smiled and really showed engagement with her body movements. There was another participant who seemed annoyed when it was her turn. After hearing the frame story, she frowned, looked away and then looked at me with an angry face. I could see that she was not comfortable, and we stopped the story session.*
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> Research journal, March 11, 2019

During the data collection, we observed the participants after the story sessions to make sure that they were comfortable with the stories they had delivered, and to see if they had any questions related to the research. During the data collection, narratives and questions often emerged at unexpected moments. For instance, I was often asked: "Can *I* now ask questions?" This would mostly happen after the story session was over. While it was disappointing from the perspective of data collection to sometimes lose these valuable accounts, I also understood that this was a meaningful incident on which to reflect as it was perhaps the result of turning off the recorder or the narratives being too confined by the frame stories. I concluded that the willingness to continue sharing and expecting to get answers to their questions even after the story session was over was perhaps an indication that they were comfortable, enjoyed the interaction with the researchers, and considered the activity and topic relevant. Perhaps their self-initiated discussions reflected that they had accessed epistemic resources that had helped them make sense of their experiences of sexual and reproductive health and rights (Fricker, 2015; Scully, 2020).

The issue of compensation was problematic, as I did not want the study to appear appealing only for the purpose of gaining a financial benefit without genuine willingness (see Grischow et al., 2021). Furthermore, a promise of significant monetary compensation to the adolescents could have led to them being forced to participate by their families in the hope of a financial gain that would then be returned to the family. The research advisory committee and I decided that all the participants, caregivers, personal assistants, and gatekeepers (community leaders and headmasters) would be given modest monetary compensation of 4 euros for the information session, which would cover their travel and time spent in the research-related activity. The adolescents who participated in the data collection sessions were given a token of appreciation in the form of school equipment, soap, menstrual pads, lotion and snacks, in the hope that these items would benefit them personally. However, we of course had no control over this.

It has been suggested that participatory disability research may become burdensome for some participants with disabilities in the global South (Katsui, 2012). I was mindful of such risks when working with the research advisory committee, and in my quest to reduce any burdens I felt that one of the success factors was that the members did not consist of over-burdened leadership figures of the Tanzanian disability movement, whose attention and energy was already stretched to multiple donors and stakeholders. Rather, the committee consisted of regional and district-level members of the disability movement, who had more time to contribute to this joint endeavor. However, this also meant that not all of them were highly educated, and this required adjusting the methods and pace of the participatory process to best respond to their characteristics. Furthermore, an evaluation form was established to determine how they felt about belonging to the committee and how their participation could be made less burdensome. This was also a way of gathering anonymous feedback for the researcher.

The committee members were compensated with a payment of 8 euros per meeting, which was negotiated with them. In addition, in the course of the meetings, which usually lasted six to seven hours on selected Saturdays, tea and lunch was provided according to their preferences. Sometimes, we also gave them small tokens of appreciation, in the form of sweets for their children, books, notebooks, and pens. The feedback discussions with the committee members and the evaluation questionnaire always raised the issue of compensation, as such issues are not taboo in Tanzania. However, the amount never became a matter that would prevent any member from participating in the meeting, which indicated that the compensation set-up was satisfactory.

4.8 Limitations

Conducting doctoral research on such a controversial and sensitive topic as sexual and reproductive health and rights meant navigating academic expectations and requirements in the local context of Tanzania. This made the methodological journey rather multi-layered, challenging and intriguing, one which required a solution-oriented approach. In the following, I describe some of the main limitations of this dissertation.

First of all, in an attempt to set realistic goals to conduct participatory research (Katsui & Koistinen, 2008) within the broad framework of sexual and reproductive health and rights, the study was confined to exploring access to services related to adolescent pregnancy and STIs, gender-based violence when accessing sexual and reproductive services, and menstrual pain as directed by the frame stories. This precluded a broad spectrum of sexual and reproductive health topics relevant to the Tanzanian context and disabilities that further research could delve into, such as forced and coerced sterilization, abortion and menstrual manipulation of adolescent females with disabilities, female genital mutilation, and obstetric fistulae and its relation to disability.

Using the method of empathy-based stories meant that the findings were primarily based on the *perceptions* of the studied adolescents rather than on their real-life *experiences*. This method was applied because talking about this topic on the basis of experiences could potentially have prevented the adolescents from participating in the study altogether. Moreover, the participants' perceptions reflected their general understanding of society and the studied phenomena in their contexts (Eskola, 1997).

Most of the participants were recruited from in-school settings and this most likely excluded adolescent females with disabilities who lived in the furthermost margins of society with no access to education. Additionally, the level of participation of adolescent females with moderate and severe intellectual disabilities remained low. Despite careful planning and preparations to respond to their characteristics, which included non-verbal communication and selective mutism, my limited understanding of persons with intellectual disabilities and limited skills to facilitate their perceptions may mean that their rich and contextualized views are being sufficiently represented in this dissertation. I concur with Flynn (2019) that "undertaking research with children with intellectual disability is a practical, ethical and creative challenge" (p. 167) that not only needs to be overcome but should be used to challenge ableist assumptions related to knowledge generation.

Finally, partnering with SHIVYAWATA, having a research assistant with disabilities and the research advisory committee supported the collection of relevant, ethical and quality data in this research (Kuper et al., 2021). However, the issue of representation must be approached with caution, as none of the above could act as representatives of the studied adolescents or whole groups of persons with disabilities (Katsui & Chalklen, 2020; Shakespeare, 2006). Despite their expert knowledge on the situation of various groups of persons with disabilities—including adolescent females with disabilities—due to their positions in the disability movement, the representativeness of their views had to be taken into consideration during the analysis and interpretation of the data.

4.9 Positionality, alterity, and power

Addressing positionality, alterity, and power distance is central in research encounters, especially in contexts such as Tanzania (Jakobsen, 2012) and when research involves marginalized groups (Secules et al., 2021). A growing body of research is critically reflecting on how external and most often white researchers enjoy privileges compared to their local collaborators and participants which reproduces asymmetrical power relations in knowledge production (Cronin-Furman & Lake, 2018; Eriksson Baaz & Utas, 2019). Such unequal power dynamics can be a threat to the safety of the participants and the credibility of knowledge production (Schulz, 2020). Next, I explain the positionalities of the researcher, and then turn to discuss how in this research I attempted to reduce my power as a researcher through two practices.

4.9.1 Researcher positionalities

Who we are as researchers shapes what can be known (Tacaks, 2003). Thus, I will first explain my positionalities. I write from the position of a white female in her late thirties, a doctoral candidate in international development studies, and a mid-career international development professional. I identify as a woman without disabilities and thus do not share the experience of disability with those with whom I collaborated in this research. I hold a Finnish passport, but for nine years I have resided in Tanzania. Through my work in international development, I spent a considerable amount of time with adolescents with disabilities during my first three years in Tanzania. This has shaped my understanding of their lived realities. Although my mind was already ideologically wired into the human rights framework, my long-term presence and experiences in Tanzania enabled me to critically approach and reflect on my approaches, as well as the implications of my global North origins for this study as I set off on the journey of *learning to unlearn* (Tlostanova & Mignolo, 2012) .

Moreover, my semi-permanent presence in Tanzania has provided me with different positionalities and confidence in employing them in research encounters. I brought forth those of my identities that established joint positionalities with the research advisory committee members and the participants, such as motherhood and spirituality. Like Jakobsen (2012), I exposed relevant cultural knowledge and utilized Kiswahili to obscure my representation as the Other. This was often unanticipated and led to a moment of surprise that acted as an icebreaker in social encounters. These aspects that blurred my position as an outsider may have broken down the typical researcher–participant dynamics and contributed to the ease of the participants.

The research assistant played an instrumental role in this study; thus, I will describe his positionalities on the basis of a positionality statement he provided. He identifies as a Tanzanian man with physical disabilities. He is in his thirties. He is an active member of communities of persons with disabilities and disability rights advocacy and was thus familiar with cross-disability-related challenges. He had prior research experience of data collection processes in two national surveys. He holds a bachelor's degree, but his skills in research ethics, data management, data collection techniques and safeguarding had to be strengthened in personalized training sessions prior to starting the research process. The research assistant facilitated many of the relationships between the author, research advisory committee, and SHIVYAWATA. He described his role in this research as a facilitator, data collector, friend, adviser, and extended family member. About his relationship with the research triad, he said: "We discuss together, we argue together, and we find solutions together. We end up working as a family by trusting each other, by knowing that this research belongs to us, and that we are a part of it."

The converging positionalities of being a researcher and a person with disabilities blurred the research assistant's representation as the Other. To the participants, he was introduced as an equal counterpart to the author. Coming across an educated person with disabilities who is employed in research, was not an everyday occurrence for the participants. To overcome otherness, he often shared his personal story to establish a connection with the participants:

> *I would introduce myself as a person with disabilities and show my leg. I would tell them that I come from a very poor home, but I believe that if a person with disabilities works hard, they can become anything. You can even become a researcher.*

Sharing his personal story may have evoked perceptions of sameness and relatability and thus assisted in distributing power to the participants, increasing their confidence in the study, and establishing trust.

4.9.2 Practices of accompaniment

"Who are we for them? Who are they for us?" (Bell et al., 1993, p. 178) are important positionality questions, and can help us understand how relationships shape research. Bergold and Thomas (2012) argue that participatory research centers around relationships. Negotiating research relationships can be complicated by a colonial history (Held, 2020), and coloniality should thus be considered in negotiations (Brunger & Wall, 2016). Adams (2014) has argued for a methodological practice of accompaniment to counteract coloniality in knowledge production. This entails engaging in daily activities and in community life to enable more ways to understand from local perspectives.

In this research, the negotiations of research relationships were evolving and open-ended (Held, 2020). The relationships facilitating and maintaining the participatory process required commitment and work. During my years in Tanzania prior to this study, I had noticed that harmony in relationships is a delicate issue, and that disharmony could easily bring a halt to any joint initiative. Acknowledging the integral value of relationships in participatory research made me considerate about sustaining and maintaining relationships both formally and informally. The formal research agenda-related relationship was maintained through the research advisory committee and stakeholder meetings with SHIVYWATA. However, the informal practices involved more non-conventional ways and required creating stakeholder relations with the members by meeting in person, sending emails and messages, calling, and participating in significant family happenings. Such correspondence and meetings took place without a predetermined research-related agenda and evolved around recognizing each other as friends and colleagues, even family, rather than through a formal research relationship.

These courtesy meetings may have initially felt less genuine, but eventually, sharing family life, discussing significant life events (e.g., weddings, funerals, graduations), and conversing about current affairs in the country resulted in enjoyable moments of connection and became central to establishing trust and commitment. The high level of commitment was shown in that there was no turnover among the members of the research advisory committee throughout the study. "It warmed my heart when one of the members said to me: 'We are together until the end of the study. […] They seemed very committed, unbelievable" (Research journal, January 26, 2019).

Accompaniment, as a rather non-conventional and interesting methodological practice, calls for denaturalizing and re-examining some of the mainstream practices and roles that traditional research has portrayed as standard, such as detachment (Adams, 2014; Bergold & Thomas, 2012). Detaching oneself physically, socially, and emotionally from the research advisory committee members could have further established the researcher as the Other.

4.9.3 Denaturalizing the researcher as the one in power

Recognizing power dynamics is important when assessing the credibility and trustworthiness of research. There is increasing concern that global North-oriented research procedures reproduce the paternalistic approach to research participants (Connor et al., 2018; Schulz, 2020). Connor, Copland and Owen (2018) claim that, for instance, conventional ethical frameworks fail to empower research participants. These processes have also contributed to binarizing the roles of the researcher and the researched (Chhabra, 2020; Thapar-Bjorkert & Henry, 2004). This in turn has strengthened the assumption that the researcher is by default the one in power. My experiences how that if the power of the (foreign) researcher is assumed, the positions of power and agency occupied by other stakeholders are rendered invisible.

In line with Schultz (2020), I noted that power over the researcher was demonstrated through, for instance, acts of protection. Various incidents occurred during the research in which the research assistant felt the need to protect me. This happened when, for instance, he considered which contacts to provide or which connections to withhold from me, which setbacks to describe in the personal or work-related realm, or when he hid harsh or insulting words that had been said in relation to my Western positionalities. The research assistant also felt the need to protect me from various financial requests from the stakeholders to the extent that he later admitted to having paid some of them from his own pocket. These acts of protection could also reflect our gendered roles and cannot be solely attributed to shifts in power imbalances.

Power over the researcher was also exercised at times when I experienced vulnerability. I do not disclose this vulnerability in an attempt to generate sympathy: My intention is to demonstrate the research collaborators' power over the researcher in this instance. For instance, when I was hospitalized during the participatory research process, I experienced first-hand the strengths of community, social reciprocity, and how the informal care networks fill in the gaps of formal care. This was manifested by, for instance, visits, prayers, well-wishes, and deliveries of nutritious food. Such gentle demonstrations of power over the researcher were a profound reminder of the fluidity of the positionalities in research of this kind. Cultivating a reflexive practice of denaturalizing the researcher as the one in power unveils power dynamics in participatory research that might otherwise remain hidden.

This chapter has explained the methodology applied in this research. Next, I present the outline of the research findings, based on my three research articles.

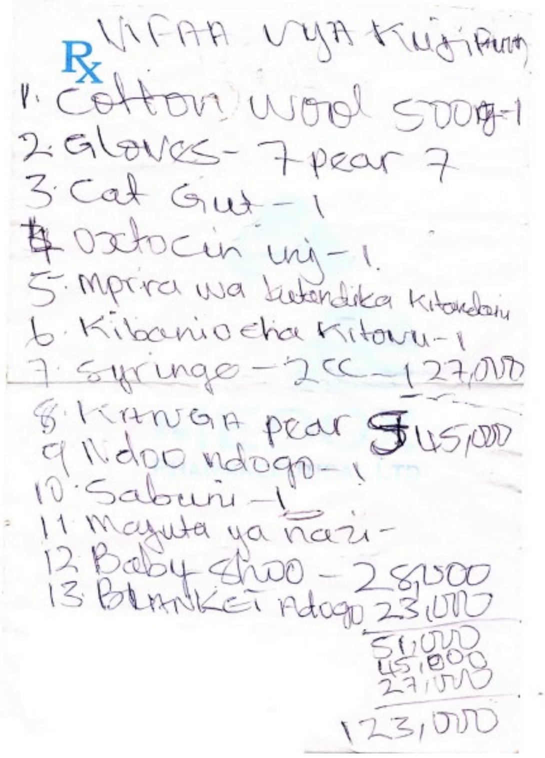
5 FINDINGS

The findings of this dissertation have been published in research articles in a peer-reviewed international research journal and in an international peer-reviewed research book. Article II is in a double-blinded peer-review process for an international research journal. Each article focuses on a specific theme to generate an understanding of the perspectives of the studied adolescents: access to sexual and reproductive health services (Article I), the interlinks between gender-based violence and access to sexual and reproductive health services (Article II), and the embodied inequalities in sexual and reproductive health and rights (Article III). I now position these three articles in this dissertation by first presenting an overview of each article's focus, methodology and findings, and then presenting the summary of the key findings that pave the way for the final discussion.

5.1 Article I: Access to sexual and reproductive health services

Article I is entitled "Disparities in Accessing Sexual and Reproductive Health Services at the Intersection of Disability and Female Adolescence in Tanzania" (co-authored by Hisayo Katsui and Richard Sambaiga). It examines the inequalities faced by adolescent females with disabilities when accessing sexual and reproductive health services in Tanzania, and explores how sexual and reproductive health service provision responds to their characteristics. The method of empathy-based stories was utilized to investigate the perceptions of 136 adolescent females with disabilities. Data was analyzed by data-driven thematic analysis.

The findings supported previous scholarly work and demonstrated that in the Tanzanian context, physical inaccessibility, communication barriers, service providers' negative attitudes, issues of confidentiality, and mistreatment are key barriers to adolescent females with disabilities accessing sexual and reproductive health services. The findings demonstrated that discrimination negatively influences access at different phases of seeking sexual and reproductive health care, starting from the family and the community. The study also produced new insights into the intersection of disability and female adolescence in the Tanzanian context. The studied adolescents' various identities simultaneously produce advantages and disadvantages related to disability and adolescence. In addition, relational aspects and collective effort are central enablers and inhibitors of access to sexual and reproductive health and rights. This may be due to finances, escorting, accessibility, the interpersonal skills of the providers, privacy, or reproductive autonomy. For instance, mobilizing resources can be a time- and energy-consuming task. An example demonstrates that the cost of purchasing the equipment[21] to ensure safe childbirth may reach 123 000 Tanzanian shillings, approximately 50 euros, as demonstrated in Figure 3. This situates safe childbirth within rigorous efforts to mobilize funds, or as completely out of reach.



VIFAA VYA Kujifungua

Rx

1. Cotton wool 5000=1
2. Gloves - 7 pear 7
3. Cat Gut - 1
4. Oxtocin inj - 1.
5. Mpira wa kutandika kitandani
6. Kibanio cha kitovu - 1
7. syringe - 2cc - 1 27,000
8. KANGA pear 5 45,000
9. Ndoo ndogo - 1
10. Sabuni - 1
11. Mafuta ya nazi -
12. Baby shoo - 28,000
13. BLANKET Ndogo 23,000

51,000
45,000
27,000

123,000

Figure 4 Costs of childbirth calculated by young woman with physical disabilities

The results also illustrated that the studied adolescents are capable of deeper engagement in their access to sexual and reproductive health service, but that the characteristics of the service providers do not support this engagement. The findings also provided evidence of how sexual and reproductive health services reflect the social dynamics of a society, namely socially normalized violence against adolescent females with disabilities.

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[21] 1) Cotton wool, 2) 7 pairs of gloves, 3) delivery blade, 4) oxytocin injection, 5) mattress topper, 6) umbilical cord clamp, 7) syringe, 8) *kanga*-cloth, 9) small bucket, 10) soap, 11) coconut oil, 12) blanket for baby, 13) small blanket. In addition to these costs, the means for covering admittance fees and food also need to be secured.

The narrative data highlighted the often-disregarded voices of adolescent females with disabilities and encouraged discussion on the role of community and the relational enablers and inhibitors of access for the studied adolescents. It was suggested that conceptualizing *affection* as an additional provider dimension of the access to sexual and reproductive health services was a "reasonable accommodation" without "undue burden" (United Nations, 2006, Article 2), and enabled adolescents with disabilities to access sexual and reproductive health services in Tanzania.

5.2 Article II: Gender-based violence in the context of access to sexual and reproductive health services

Article II drew on the analysis of the first article and its findings related to violence in the context of sexual and reproductive health service access. It enabled a more in-depth investigation of the interface of sexual and reproductive health service provision and gender-based violence. Article II is entitled "Rethinking Gender-based Violence in the Context of Access to Sexual and Reproductive Health Services: Perceptions of Adolescent Females with Disabilities in Tanzania." The methods and data utilized were the same as those used for the Article I, with a specific analytical focus on violence. This was the first known study in Tanzania to explore how gender-based violence intertwines with access to sexual and reproductive health services from the intersectional perspective of disability and female adolescence.

The findings demonstrated that the forms of gender-based violence in the context of accessing sexual and reproductive health services entailed emotional, physical, economic, and sexual violence, and introduced inaccessibility as a form of structural violence when accessing these essential services. Inaccessibility can take multiple forms, one of which is the inaccessibility of buildings, as demonstrated in Figure 4, which depicts the challenges of girls and women who are wheelchair users when they access the maternity ward on the second floor of a regional hospital in which the elevator does not work. Furthermore, collective dynamics, such as the role of support networks, were found to be pivotal for accessibility and protection, and were valued by the studied adolescents over independence. The findings identified gaps in the contextualized links between access to sexual and reproductive health services and gender-based violence which posed conceptual challenges. These in turn are seen as resulting in services that are not fit-for-purpose for adolescent females with disabilities.

The study suggested that the conceptualizations of violence in the context of accessing sexual and reproductive health services need to be more specific. They should not all be placed under the broad category of gender-based violence (Chadwick, 2021): They should be approached through intersectional perspectives (Chadwick and Jace Mavuso, 2021). These perspectives could be further used to identify and address the specific violence located at the site of gendered violence when accessing sexual and reproductive health services. Applying more nuanced conceptualizations in this critical area of research is of paramount importance for unveiling and addressing the discrimination, non-consensual care, and abuse that underpin the experiences of adolescent females with disabilities worldwide. The findings also contribute to disability and development theorizations that draw from collective dynamics that can complement, expand and enrich the human rights model beyond the rights paradigm of the global North when it comes to sexual and reproductive health and rights and disability.

Figure 5 Inaccessibility of the second-floor maternity ward at a study site.

5.3 Article III: Embodied inequalities in sexual and reproductive health and rights

Article III focuses on exploring embodiment and sexual and reproductive health and rights through the lens of menstrual pain. The article, entitled “Menstrual

Pain Realities of Young Females with Disabilities In Tanzania: Towards a Nuanced Understanding of Pain and Embodiment", was co-authored by Magdaleena Lehmuskoski, Hisayo Katsui, and Richard Sambaiga. It was published as a chapter in an international research book entitled "Embodied Inequalities in Disability and Development", edited by myself and Hisayo Katsui.

Menstrual health is an overlooked yet critical area in the context of sexual and reproductive health and rights. Menstrual pain affects three quarters of young females (Armour et al., 2019). It interferes with daily activities and causes emotional distress. Very little is known about menstrual pain through the intersectional perspectives of disability and its effect on the well-being of young women with disabilities. Pain is an intriguing lens from the perspective of disability theorizations, as the social model of disability is suggested to have contributed to binarizing disability and impairment (Rohleder et al., 2019). The study counteracted the binary of body and mind, self, and others from the epistemological standpoint of Tanzanian females with disabilities, to explore a more nuanced view of disability and impairment as well as health and well-being. Menstrual health was one of the priority areas of the study, as identified by the research advisory committee, and was therefore included in the research agenda.

The perspectives of 63 young Tanzanian females with disabilities were captured through the method of empathy-based stories, which enabled the collection of rich data on the socio-cultural aspects of disability embodiment. This data set was different to those used in Articles I and II and was collected using frame stories that focused on menstrual health and well-being. The participants were mainly adolescents, but young females up to the age of 24 were also included. As pain dominated the menstrual narratives of the participants, a focused analysis of menstrual pain perceptions was conducted. Centralizing pain enabled disability embodiment to be explored in the context of sexual and reproductive health and rights, by investigating how impairment effects and disablism are perceived within the context of menstrual pain, and how impairment effects and disablism impact psycho-emotional well-being.

The social relational model of disability (Reeve, 2014; C. Thomas, 1999) provided theoretical and conceptual inspiration for the menstrual pain narratives. Novel approaches to understanding disablism, impairment effects and psycho-emotional disablism emerged, producing a more nuanced view of disability embodiment. We found that pain, conceptualized as both a disability and an impairment, weaves together the social and the individual, the body and the mind, into disability embodiment. Menstrual pain impacts both public and private lives by adding a layer of oppression to the disability experience. Some aspects could not be explained through the social relational model. For instance, menstrual pain was linked to gendered conditioning that socially characterizes the season of adolescence. These conditioning processes consist of hardening, managing womanhood, disapproval of laziness, and good manners (*adabu*). This conditioning also involves pain denial, and young females with disabilities pursuing the achievement of full social personhood and attaining a contributory role in the family and the community, which enhances their sense of identity and meaning and in turn enables and sustains their health and well-being.

These findings were discussed through a decolonial lens, contributing to the theoretical discussion on who belongs to and who counts as a full member of society. Such discussion is pivotal when it comes to the intersections of disability, gender, and adolescence, especially in contexts in which people do not typically perceive well-being, sense of entitlement, and worth through a human rights lens.

Table 7 Summary of articles

Article	I	II	III
Aim	To understand the inequalities faced by adolescent females with disabilities when accessing sexual and reproductive health services	To investigate the contextualized links between access to sexual and reproductive health services and gender-based violence	To explore disability embodiment and sexual and reproductive health and rights inequalities through the lens of menstrual pain
Research questions	a) How do adolescent females with disabilities perceive the accessibility of sexual and reproductive health services? b) What characterizes their abilities to access sexual and reproductive health services?	How are disability and female adolescence intertwined with exposure to gender-based violence when accessing sexual and reproductive health services?	a) How are impairment effects and disablism perceived within the context of menstrual pain? b) How do impairment effects and disablism impact psycho-emotional well-being?
Methods and data	257 empathy-based stories by 136 adolescent females with different disabilities (aged 10 to 19)	257 empathy-based stories by 136 adolescent females with different disabilities (aged 10 to 19)	126 empathy-based stories by 63 young females with disabilities (aged 12 to 24)
Key findings	a) Physical inaccessibility, communication barriers, negative attitudes of service providers, lack of confidentiality, and mistreatment are the main barriers to access. b) Discrimination affects access across different phases of seeking sexual and reproductive health care. c) The studied adolescents' various identities simultaneously produce advantages and disadvantages. d) Collective dynamics are pivotal for sexual	a) The intersectional perspectives of disability and female adolescence challenge the existing conceptualizations of gender-based violence. b) Emotional, economic, physical, and sexual violence are the most prevalent forms of gender-based violence when accessing sexual and reproductive health services. c) The inaccessibility and inappropriateness of communication in this unique site of	a) Menstrual pain adds another layer of oppression to the disability experience. b) Pain realities were intense, yet pain management strategies remained insufficient. c) Pain relief was not accessible or affordable due to low economic status and lack of menstrual knowledge. d) Pain weaves the social and the individual, the body and the mind into disability embodiment.

	and reproductive health care access, yet they may also constrain access. e) The characteristics of the service providers do not respond well to those of the studied adolescents.	violence are depicted as structural violence. d) Collective dynamics are pivotal for accessibility and protection and are valued over independence. e) Asymmetrical obligations (vs. reciprocal obligations) sustain accessibility and protection.	e) Pain denial is a pathway for young females with disabilities to navigate amidst the potentiality of personhood. f) Menstrual pain is linked to the gendered conditioning of becoming a full member of community. g) Collective dynamics enabled and sustained the health and well-being of the studied adolescents.

5.4 Summary of key findings

The findings across the three articles highlight the role of collective dynamics and socio-cultural factors in sexual and reproductive health and rights at the intersection of disability and female adolescence. The unique role of relationships that permeates the perspectives of the sexual and reproductive health and rights of adolescent females with disabilities cuts across the principal findings. Below, the key findings of the articles are abstracted and summarized into three overarching themes that capture their essence, explain the studied phenomena, and answer the research questions (Thompson, 2022): (1) *Belonging*: The collective dynamics that mediate the realization of sexual and reproductive health and rights; (2) *Becoming*: The logics of inclusion and exclusion; and (3) *Knowing*: Revaluing intersectional and embodied disability perspectives.

Table 8 First theme of key research findings: Belonging

Belonging: The collective dynamics that mediate the realization of sexual and reproductive health and rights	**Article**
Collective dynamics are a significant resource for advancing sexual and reproductive health and rights.	I, II, III
Overcoming barriers to accessing sexual and reproductive health services in settings where no formalized support systems are available requires more than an individual claiming their rights.	I, II
Informal networks of care, such as family and community, are perceived as the most reliable support system.	I, II
These informal networks provide finances, mobility support, communication, and safeguarding to ensure access to sexual and reproductive health services.	I, II
Accessibility is strongly linked to interdependence and relationality.	I, II
Protection from violence relies on the collective dynamics of problem-solving.	II
The framing of collective dynamics in research on accessibility to and protection in sexual and reproductive health services suffers from shortcomings.	I, II
The design and provision of sexual and reproductive health services are based on individualism and constrain the sense of community and collective dynamics that enable access to services.	I, II
The lack of reliability, and the time and energy required for mobilizing collective resources highlights the accountability issues in the collective and informal support systems.	I
An individual cannot realize their sexual and reproductive health and rights or claim these rights: This is influenced by relationships and collective decision-making.	I, II, III

The perspectives of the studied adolescents depicted that belonging to a community and familial networks is an intrinsic part of existence, and a key to understanding how the collective dynamics and informal networks of care fill in the gaps in formal sexual and reproductive health service provision and protection against violence. This underscores the fact that the advancement of sexual and reproductive health and rights is affected not only by legal and policy frameworks and their implementation, but also by what is contextually understood in the Swahili culture and philosophy as *utu*: common humanity and full social personhood (Fay, 2016; Rettová, 2020). Various social, economic, and personal entitlements flow from this belongingness to humanity and contribute to the advancement of sexual and reproductive health and rights.

Despite the strengths of the collective approach, it also has constraints. The reliability of the informal networks of care as well as the effort to mobilize support and funds remain a challenge. The findings also demonstrated that the highly individualized design of sexual and reproductive health service provision does not support the collective dynamics and informal networks of care consisting of families and communities. This centralizes the paradox of individualism in sexual and reproductive health services. Furthermore, it highlights the question of the informal accountability mechanisms of communities and families towards adolescent females with disabilities. It focuses attention on the socio-cultural norms and conceptions of disability and female adolescence that govern the accountability of such informal systems of support.

Autonomous reproductive decision-making was also a paradox, according to the findings. Decision-making was portrayed as collective by nature, as reproductive decision-making flows from the interaction between individuals and society, which is similar to the trans-subjective approach to autonomy of Romero et al. (2020), who view the processes of autonomy related to transitioning to adulthood from the perspective of the interaction between individuals and their society. Such an approach analyses the individual's belonging to and participation in community life. The socio-cultural aspects of the unique season of adolescence and the social expectations related to the transition to adulthood and attaining personhood are important in this approach, as discussed next under the research theme of becoming.

Table 9 Second theme of key research findings: Becoming

Becoming: The logics of inclusion and exclusion	**Article**
Reaching social personhood can be facilitated through gendered conditioning and contribution to family and community life.	III
Understanding social personhood-as-endowed morally obliges community members to protect and ensure the sexual and reproductive health entitlements of adolescent females with disabilities.	I, II, III
Charity, whether through reciprocity or asymmetrical obligations, is perceived as a positive aspect of community living, and an opening for community membership for those granting or receiving it.	II
Negative sexual and reproductive health outcomes may jeopardize social becoming.	I, III
Sexual and reproductive health services reflect socially normalized sexual violence against adolescent females with disabilities.	I, II

The studied adolescents’ exposure to transactional sex and sexual exploitation was depicted as the result of financial dependency and the desire for privacy in sexual and reproductive health services.	I, III
Distinct forms of violence due to the particular features of sexual and reproductive care, and the power distances between the studied adolescents and the service providers, call for an in-depth, nuanced understanding of the violence that occurs in these services.	II
Concerns for personal safety are linked to sexual maturity, and begin from menarche. They lead to hiding and denying menstrual pain.	III

The embodied and social transformations shaped by adolescence, menarche, and puberty are part of the second theme of the key research findings: becoming. Becoming characterizes adolescence in an embodied and social sense and highlights the logics of inclusion and exclusion. As the onset of menarche was understood as sexual maturation and a physical change, the singular view of sexual and reproductive health and rights were also portrayed as disrupting the gendered norms of social becoming (see Fay, 2016). The findings linked to this theme also contribute to understanding the personhood of persons with disabilities in accordance with the African communitarian philosophy, in which becoming is one way to conceptualize attaining personhood (Gyekye, 1987, 2004; Imafidon, 2021; Menkiti, 1984; Nyamnjoh et al., 2021). Becoming also depicts a processual view of personhood that is pertinent to the Swahili culture and philosophy of “life is the process of becoming a person and acquiring humanity through building relationships with others” (Rettová, 2020, p. 33).

Moreover, the findings demonstrated the logic of inclusion and exclusion based on age, gender, and disability. An adolescent female with disabilities may obtain an opening for personhood, or full social membership, through earning personhood by abiding their social and moral obligations, including gendered roles. This implies that personhood can be earned by enduring or denying pain, and by contributing to family and community life. This, however, is not attainable for many adolescents with severe or multiple disabilities, for instance. Therefore, the conceptualization of “personhood-as-acquired” (Menkiti, 1984; Nyamnjoh et al., 2021, p. 3) holds community and family members to a high moral standard, as their character is formed and personhood achieved through morally obliged actions (Nyamnjoh et al., 2021). As community members express humanness through charity, compassion, solidarity, and affection, they are also granted personhood.

A hierarchy of persons, implying that disability and female adolescence close off the potentiality of personhood and devalue them as less than persons, resulted in grave depictions of violence throughout the findings. Violence was portrayed as inhibiting the sexual and reproductive health and rights of the studied adolescents. Furthermore, the potentiality of personhood, of becoming a person, may be jeopardized for victims of violence through, for instance, unwanted pregnancies or STIs associated with risky or socially disowned sexual behavior.

Understanding the logic of inclusion and exclusion through the concept of personhood in African communitarianism can expand the theoretical frames that are currently used to explain sexual and reproductive health entitlements.

Table 10 Third theme of key research findings: Knowing

Knowing: Revaluing intersectional and embodied disability perspectives	**Article**
Intersectional perspectives reveal the interaction between the invisible or neglected social categories that influence the realization of sexual and reproductive health and rights.	I
Various social categories compound with disability and female adolescence and influence the realization of sexual and reproductive health and rights (e.g., marital status, age, disability type, education, frequency of pregnancy, poverty, and how the pregnancy was initiated (e.g., in a relationship or through violence)).	I, III
An intersectional perspective supports the unravelling of gender-based violence for the purpose of recognizing all its forms in the context of sexual and reproductive health services.	II
Recognizing the various normalized modes of information, communication, and infrastructure as structural violence calls for reconceptualizing the inaccessibility of sexual and reproductive health services as a form of gender-based violence.	II
By rejecting these normalizations, the perspectives of adolescent females with disabilities and their knowledge regarding gender-based violence in the context of sexual and reproductive health services are revalued.	I, II
Normalized menstrual pain hinders the urge to find pain management options and subsequently excludes, denies participation, increases health risks, and alters the psycho-emotional well-being of young women with disabilities.	III
Internalized oppression and its influence on sexual and reproductive health and rights is revealed and can be addressed through the internalized view of adolescent females with disabilities as unacceptable clients of sexual and reproductive health services.	III
The intersectional perspective of disability and female adolescence provides a nuanced and less binarizing perspective of the self and others, and the body and mind.	III

The third theme, knowing, is based on my analysis which found that exclusion, and the related sexual and reproductive health violations, are also related to intersectional knowledge deficits. The findings displayed the importance of understanding the contextualized social and embodied constructs of age, gender, and disability in informing about adolescents' sexual and reproductive health entitlements, such as access to services or freedom from violence, and inclusion in society. The third theme of knowing highlights the relevance and value of the marginalized, intersectional, contextual, and embodied perspectives. The findings demonstrate that diverse ways of knowing invite alternative understandings of embodiment, well-being, and health, and that this is essential for counteracting the coloniality of knowledge at the intersections of the global and local discourses on sexual and reproductive health and rights.

For instance, the findings demonstrated that the perspectives of the studied adolescents challenged the current conceptualizations of access, violence and embodiment, and provided more accurate frames for identifying, resisting, and addressing the normalization of unrealized sexual and reproductive health and rights. Furthermore, the intersectional knowledge based on disability and female adolescence challenged the normalization of inaccessibility in the context of sexual and reproductive health and rights services. Thus, embodied and intersectional disability perspectives may not only provide a vital resource for realizing sexual and reproductive health and rights, but a resource without which structural, systemic and *epistemic violence* (Dotson, 2011) prevails. This is aligned with Ned's (2022) view that if the disability perspective is neglected in African knowledge creation, "we run the risk of translating the existing epistemic violence into other forms of structural and systemic violence"(p. 486).

5.5 The cycle of belonging, becoming, and knowing: Sexual and reproductive health and rights through the perspectives of Tanzanian adolescent females with disabilities

This chapter ends by synthesizing the findings in order to respond to the research questions presented in the introduction chapter. I asked: How are sexual and reproductive health and rights portrayed through the perspectives of adolescent females with disabilities in Tanzania? And more specifically, how do the perspectives of adolescent females with disabilities portray collective dynamics as sustaining or constraining their sexual and reproductive health and rights? How do the studied adolescents' perspectives demonstrate the logic of inclusion and exclusion within sexual and reproductive health and rights? And how could the intersectional perspective of disability and female adolescence inform the realization of sexual and reproductive health and rights in Tanzania?

I found the human rights framework to be insufficient for framing the perspectives of the studied adolescents. Based on this, the notions of belonging and becoming became key to understanding the perspectives of Tanzanian adolescent females with disabilities of their sexual and reproductive health and rights. The notion of belonging emerged in the sense that sexual and reproductive health entitlements related to services, information, or protection are activated through social relations and flow from belonging to familial and community networks. Belonging also activates a sense of worth.

The notion of belonging is key to understanding the collective dynamics that enable or constrain the advancement of reproductive health and rights. Informal networks of care fill the gaps in the formal sexual and reproductive health service provision and protection against violence. Some social, economic and personal entitlements are activated and flow from belonging. Furthermore, reproductive decision-making is influenced by relationships and is collective. Within the collective support systems, the lack of reliability raises the issue of accountability. I also found that service design and provision are based on individualism and that they are in conflict with the sense of community and collective dynamics that would enable the studied adolescents' access to services. Understanding the collective dynamics in relation to sexual and reproductive health and rights can complement, enrich, and expand the human rights model.

Sexual and reproductive health and rights are also portrayed through the notion of becoming, which illustrates how the potentiality of social personhood is mediated by a person's disability, age, and gender. The notion of becoming is key to understanding the logics of inclusion and exclusion. The socio-cultural, gendered processes of becoming and the establishing of worth of adolescent females with disabilities can be understood through the concept of personhood, which draws from African communitarian philosophy. As productivity, contribution, respect, self-discipline, endurance, and pain denial are all social prerequisites for reaching full social personhood, attaining this personhood may be difficult for adolescent females with disabilities due to characteristics related to their disability, age, and gender. Disability adds another layer of complexity to the social and physical becoming of adolescent females in the context of sexual and reproductive health and rights. It may affect their physical becoming in the sense that unsafe childbirth, STIs, or violence will have long-term negative implications for their health or even generate additional impairments that further complicate their social becoming. Disability may also complicate their social becoming in the sense that their disability may be used to deny them access to significant life events or transitions, the opportunities to contribute, or the entitlements related to sexual and reproductive well-being.

While sexual and reproductive health and rights are understood as a disruption of the norms of social becoming (Fay, 2019), negative sexual and reproductive health and rights outcomes such as unwanted pregnancy, lack of knowledge on menstrual health management, and STIs may also hinder social becoming. This in turn may compromise the processes of belonging, through which sexual and reproductive health entitlements flow. Moral values could therefore be utilized to remedy the cultural conceptions and perceptions of adolescent females with disabilities, as could addressing the singular normative order and understanding of sexual and reproductive health and rights that is based on international human right frameworks.

Finally, the findings depicted that exclusion and unrealized sexual and reproductive health and rights are based on intersectional knowledge deficits.

The intersectionality of disability, gender and adolescence generated knowledge that could help people recognize, address, and reject the normalization of unrealized sexual and reproductive health and rights and the various related aspects. Such intersectional knowledge reveals conceptual gaps, and public and private oppressions related to sexual and reproductive health and rights while challenging the normalization of pain, inaccessibility, and narrow understanding of violence. The intersectional perspective of disability and female adolescence brings pluralism into the local and global discourses of sexual and reproductive health and rights and disability models, by introducing a contextualized, relational, and collectivistic approach. The intersectional perspective of disability and female adolescence also challenges what is known and how it can be made known by unveiling ableist, gendered, and ageist assumptions related to knowledge production. The cycle of belonging, becoming and knowing illustrates the synthesis presented here (Figure 5). It presents an abstract process, but the reality is often much more complex and non-linear.

Based on this analysis, a nuanced understanding of sexual and reproductive health and rights could be promoted in contexts like Tanzania by, for instance, centering belonging as *social well-being* in the contextualized definition of sexual and reproductive health (United Nations, 2014; WHO et al., 2017). This is based on the conclusion that, when it comes to adolescent females with disabilities, relational and social aspects of well-being have the potential to positively influence the other areas of sexual and reproductive health. The following chapter presents an in-depth discussion on these findings, as well as the conclusions and contributions of this dissertation. I end with suggestions for future research.

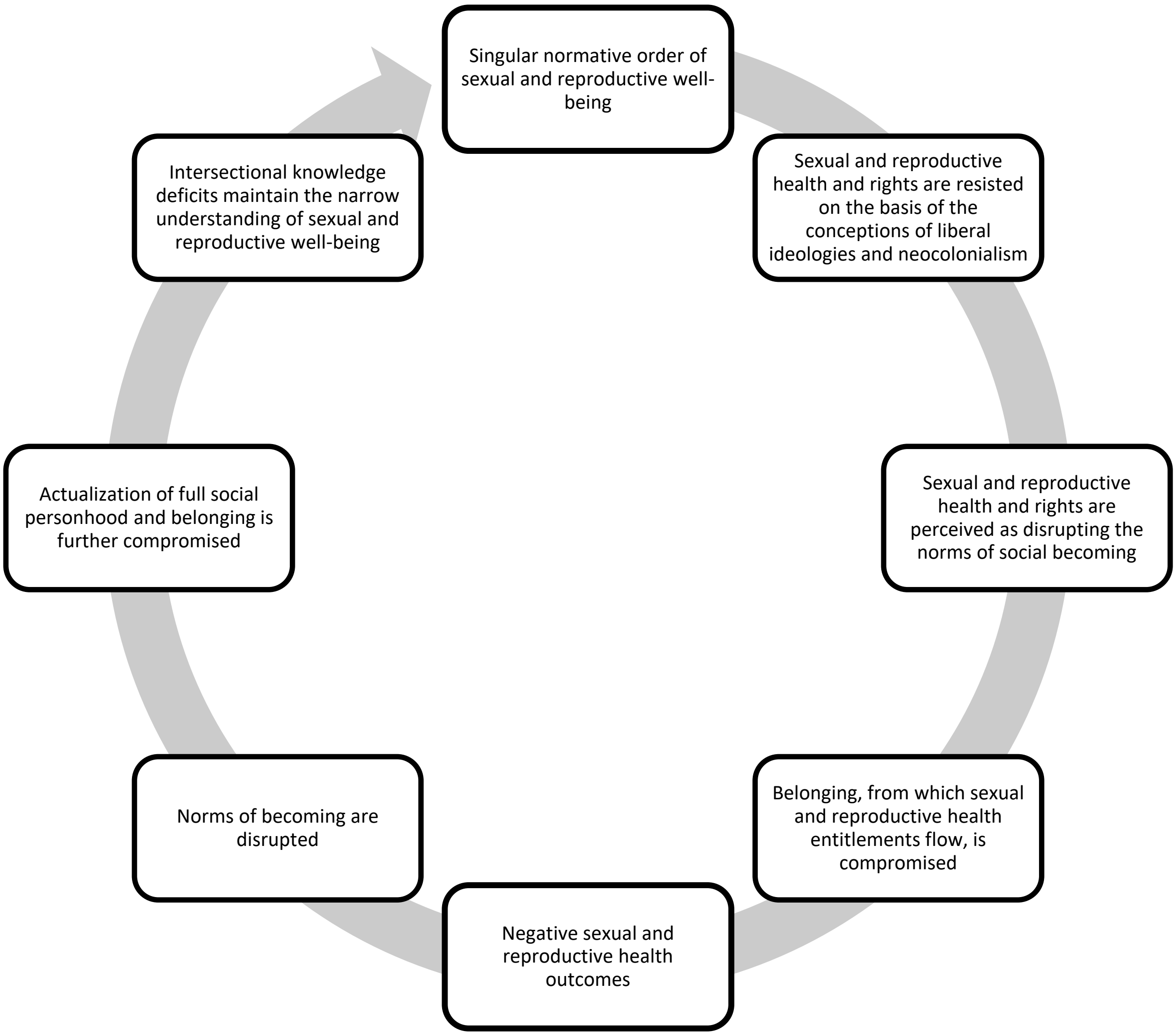

Figure 6 Cycle of belonging, becoming, and knowing: Perceptions of sexual and reproductive health and rights of adolescent females with disabilities in Tanzania

6 DISCUSSION AND CONCLUSIONS

This chapter begins with an in-depth discussion on the findings presented in the previous chapter. Then, it looks at the contributions of the study and suggests ideas for further research. The discussion that follows is situated between prevalent development and disability discourses that draw from international human rights (Berghs et al., 2019; Degener, 2017; Lawson & Beckett, 2021; Series, 2020; Yamin & Maleche, 2017) the social model of human rights (Berghs et al., 2019; Lawson & Beckett, 2021), and criticism of their shortcomings in terms of advancing the well-being of the majority of persons with disabilities globally (Shakespeare, 2014). It also takes into account the claims that the dominant models of disability perpetuate neocolonialism, mainly through their ideologies of individualism, universalism, and neoliberalism (Connell, 2011; Grech, 2015; Meekosha, 2011; Rao & Kalyanpur, 2020).

I discuss the findings of the study and reflect on these issues through the concepts of belonging and personhood, as these emerged from the analysis as an opportunity to lay conceptual and theoretical foundations for the worth, inclusion, and exclusion of adolescent females with disabilities. I recognize the dangers of essentializing or exoticizing the African community. In my attempt to avoid this, this chapter also serves as a platform for the voices of the research advisory committee members, to emphasize the multiple layers of identities and complexities of Tanzanian communities, and the lived realities of persons with disabilities.

Based on the empirical work conducted for this dissertation, I argue that between these two views there is demand and ample space for reconceptualizing and reimagining disability justice from an Afrocentric standpoint, which would better take into account the sexual and reproductive health, well-being and entitlements in the studied context. I base my argument on the resistance to human rights that I encountered multiple times in the course of this research. Access to the studied adolescents was regulated by government officials, guardians, and teachers. The initial response to the research was mostly negative. The term *rights,* which was included in the heading of the research permit letter and the written consent form, was considered problematic: The initial response to the research was complicated by rights language. On several occasions, the officials and guardians raised their concerns about the sexual and reproductive rights agenda. These clashing views are well illustrated in the following account of an encounter by the research assistant: "I was in this government office, and the official looked at the letter and said: 'So, you are working under the Europeans? You want to tell the girls about homosexuality?'". Furthermore, the guardians whom I met during the consent process also raised concerns about the human rights agenda. The following account by the research assistant shows this:

> They [guardians] only heard the words sex and reproduction. As people who are not familiar with research and ethical codes of conduct, they became very afraid. […] after explaining thoroughly what this research was about, they were like: 'Why didn't you tell us this in the first place? All of this we can agree with! Why did you have to talk about rights?'

These concerns or related resistance did not once result in refusal to grant consent, but the cultural and social norms around sexuality and maturation were perhaps rendered visible (see Fay, 2019). Drawing from this discovery and other findings of this dissertation, I next attempt to contribute to pluralism in the disability models, which could compel social justice in policy, practice, research and eventually also in the sexual and reproductive health of Tanzanian adolescent females with disabilities.

6.1 Belonging as social inclusion

Despite the potential of the human rights model to reconceptualize what it means to be a human, formal and informal support, and the ethic of belonging (Quinn & Arstein-Kerslake, 2012, p. 37), this dissertation presents the human rights framework as insufficient for framing the perceptions of adolescent females with disabilities of their sexual and reproductive health entitlements. Firstly, the human rights model has a distinct function as a model for disability policy rather than a conceptual model (Lawson & Beckett, 2021). Secondly, it does not easily permeate contexts in which rights are not the primary means of granting entitlements (Undie & Izugbara, 2011). Third, it does not respond to the claims of many collectivist cultures as it fails to frame disability from a thoroughly relational perspective. Fourth, the human rights model's logic is based on rights holders being able to claim their rights individually or collectively (Lawson & Beckett, 2021).

The social model of disability in turn has a different function; it is a model of disability, an heuristic and descriptive device, to guide discoveries related to social barriers in different contexts (Lawson & Beckett, 2021). The social model provided insights into the contextualized understanding of the barriers in the perspectives of adolescent females with disabilities in Tanzania. It helped me discover the barriers to belonging to family and community, and the worth bestowed by belonging. According to the social model, belonging is "generated by a *shared experience of disablement* through exclusionary societal structures, attitudes and practices and by a shared commitment to resistance and social change" (Lawson & Beckett, 2021, p. 366, emphasis by the author). Furthermore, as Bezzina (2020) argues, social model thinking may need a welfare state to justify it. Thus, neither one of these models would fully provide frames to explain the realities portrayed through the perspectives of the studied adolescents. In accordance with Katsui (2012), for individuals at the very margins of a society that is not a welfare state, who in many ways struggle from day to day to meet their basic needs, and are excluded from others who share the experience of disablement, mobilizing for social movement, for claiming rights or holding duty bearers accountable often remains a distant or irrelevant aspiration.

The findings demonstrate that sexual and reproductive health is based on the sense of humanness and belongingness. In fact, in line with Standing et al. (2011), and Undie and Izugbara (2011), belonging may have deep implications for entitlements to sexual and reproductive health, such as reproductive choices and access to services—perhaps much more so than formal laws have had. Based on the findings of this dissertation, I claim that questions of belonging may be theoretically enriching in the context of disability and development and may open new conceptual horizons for the inclusion of adolescent females with disabilities in the entitlements related to sexual and reproductive health in Tanzania and beyond.

However, the concept of belonging is not new for attempting to understand the social inclusion and exclusion of persons with disabilities (Allen & Kern, 2017; R. Barnes et al., 2021) and is recognized as central to well-being (Nagel, 2011; Warr, 2015). Although several scholars have addressed the theories of belonging of persons with disabilities (E. Hall, 2010; Mahar et al., 2013; Milner & Kelly, 2009), their theorizations have emphasized the role of the individual, positioning relationality under belonging as one theme among others such as identity, place, and contribution (Strnadová et al., 2018). Furthermore, some global North theorizations have presented belonging as an outcome of social inclusion (Cobigo et al., 2016). A stronger relational understanding of belonging is gaining ground and "has implications for the ways social inclusion is enacted. It demands, that in addition to securing rights and opportunities, we also address social, cultural and attitudinal barriers that hinder a sense of belonging" (Reeves et al., 2022, p. 10).

Despite these conceptual and theoretical advancements, the positionings of belonging inadequately place the role of relationships and community above that of the individual, as was demonstrated in my analysis. Instead, they highlight the greater role of the individual, above that of the community and relationships. Thus I concur with Fulton et al. (2021), that there is a call for more nuanced conceptualizations of belonging, and with Reeves et al. (2022), that there is a demand for theorizing belonging in its relation to the social inclusion of persons with disabilities. Furthermore, in the quest to understand belongingness from an Afrocentric disability perspective, the social model and the human rights model may not be sufficient, as demonstrated. Remedying these conceptual and theoretical shortcomings should begin by drawing from knowledge on belonging and disability in the

African contexts, because, as a mere tenet of social inclusion, it does not do justice to the role of belonging depicted by the participants of this research.

6.2 Framing belonging and social inclusion through African communitarianism

Although I have referred to many global North originated concepts in this dissertation, the empirical research led me to recognize African concepts that may be more applicable to framing the discussion on sexual and reproductive health and rights in the context of disability, gender, and adolescence in Tanzania. My positionalities contribute to this recognition in the sense that, as a human research instrument with nine years of experience of living in Tanzania, I have observed and experienced the wealth of knowledge and care in Tanzanian communities. Thus, I agree with Grech (2011a), Ned (2022), and Rao and Kalyanpur (2020), that this knowledge and care remains unrecognized, under-theorized, and under-harnessed by scholars, policy-makers, activists, health practitioners, and human rights and development professionals.

Due to various structural barriers, Afrocentric theorizing has only recently begun to gain prominence in academia beyond the global South. To accelerate the development of Afrocentric disability models, African experiences of, and voices and knowledge on disability should be centered (Ned et al., 2022). This participatory research attempted to provide such a platform, albeit a limited one, to center Tanzanian voices on disability. I wish to further emphasize the importance of centering these voices by including excerpts from the research advisory committee proceedings and from empathy-based stories as I discuss the Afrocentric disability theorizations related to belonging in the following sections.

Issues of belonging, worth and social inclusion of persons with disabilities are often framed by the African communitarian philosophy, which stems from African humanism. It is an existential, moral and political philosophy that forms the foundation of the African way of living and identity, a basis on which communities can thrive, and it distinguishes the African culture from non-African cultures (Gyekye, 1987; Imafidon, 2021; Menkiti, 1984; Nyamnjoh et al., 2021). It outlines the African understanding of personhood as thoroughly social and community based (Etieyibo & Ikuenobe, 2020). As Rettová (2020) posits, "the individual is tied to the social fabric and defined through the community" (p. 32).

A certain incline in African scholarly literature suggests that the concepts of African humanism such as belonging, interdependence, relationality, connectedness, and humanness, which are grounded in African communitarian philosophy, may be beneficial for enhancing the value and well-being of persons with disabilities. For instance, the concept of *ubuntu*, humanness, has framed research on the contextualization of the SGDs (van Norren, 2022), revaluing persons with disabilities (Berghs, 2017; Imafidon, 2021; Ngubane-Mokiwa, 2018), parenting (Shambare, 2022) and the inclusion and protection of children with disabilities

(Bannink Mbazzi et al., 2020; Nyamnjoh et al., 2021). It has also framed health interventions responding to the COVID-19 pandemic (Chigangaidze et al., 2022), protecting women and girls with disabilities from violence (Chisale, 2022), gendered care (Chisale, 2018), and advancing sexual and reproductive health (Tarkang et al., 2018) and adolescent sexual and reproductive health service provision (Nunu et al., 2022). This indeed illustrates that the African communitarian philosophy has gained prominence as a theoretical resource for framing various social and political issues related to disability (Imafidon, 2021).

The key concepts of African communitarian philosophy are community and personhood. First and foremost, individuals are inseparable from community. While in European philosophies, community is often conceptualized as secondary, as a union of individuals, African communitarianism constructs personhood by starting with the community. "It is not the 'I' that constructs a 'we' but a 'we' that constitutes an 'I'" (Rettová, 2020, p. 33). Mbiti (1969) describes this central tenet of the interconnectedness of community and the individual as follows:

> Only in terms of other people does the individual become conscious of his own being, his own duties, his privileges and responsibilities towards himself and towards other people. When he suffers, he does not suffer alone but with the corporate group; when he rejoices, he rejoices not alone but with his kinsmen, his neighbours and relatives whether dead or alive. Whatever happens to the individual happens to the whole group and whatever happens to the whole group happens to the individual. The individual can only say: 'I am, because we are; and since we are, therefore I am.' This is the cardinal point in the understanding of the African view of man. (pp. 108–109)

Against this backdrop of understanding community as constituting a person, being an all-encompassing thoroughly intrinsic part of life and meaning-making (Wissing et al., 2020), the denial of belonging to a community through the practice of segregation and hiding of children with disabilities, whether in the name of protection or as a result of stigma, may be one of the most devastating ways to strip away human worth and dignity. It removes a person with disabilities from the very source of what constitutes a person: human engagement. Some of the most overwhelming examples that emerged in this research, were daily living being restricted to the confines of one's home, being tied to one's bed during days of menstrual flow, one's community participation and movement being limited, and access to significant rites of passage and important life and community events being denied:

> I want to say something about traditions, our traditions are very oppressive towards people with disabilities, it is a big problem. Society can even segregate people without disabilities, but it [segregation] is a bigger problem when it comes to people with disabilities. Even if she happens to get pregnant, you will maybe not hear about it until after she gives birth. Marriage for persons with disabilities is a real challenge. Society's understanding of marriage to a person with disabilities is something I can't comprehend. That is why a lot of women with disabilities are forced to have children out of wedlock and continue to live at home [with parents or relatives]. This is caused by our oppressive traditions.
>
> Woman with albinism, member of the research advisory committee

> When I wanted to get married, I found a girl, she loved me, but her father said he can't have his daughter marry a person with disabilities. So, they chose someone for her to marry. But the girl was very determined, and her family and friends liked me. I got to marry her. But the father never came to the wedding.
>
> Man with physical disabilities, member of the research advisory committee

It is important to acknowledge that the issue of African communitarianism providing a theoretical frame for the inclusion of persons with disabilities remains unresolved by African disability researchers and philosophers (See e.g., N. Z. Manzini, 2018; Ngubane-Mokiwa, 2018; Onazi, 2020). African communitarian philosophy also has other limitations. It has been criticized for its tendency to invalidate individual agency, and blamed for justifying authoritarianism, as community is portrayed as having power over the individual (A. Appiah, 1992; Wiredu, 1980). However, these critical views have led to further theorizations and the development of radical and moderate perspectives of African communitarianism. In the following, I discuss these two views and how worth and personhood are framed through them.

6.3 Implications of the Swahili concept of *utu* for disability, personhood, and human worth

> Research assistant: "What advice would you give doctors attending girls with disabilities?"
>
> A deaf girl, aged 15, Study participant: "I would advise them that people with disabilities should be valued *because they are also persons*[22]".

The collective notions of personhood that emerged through the research findings are distinct from the notions of personhood offered by the human rights model and those underpinning the social model. Here, I turn to reflect on how African communitarianism establishes the worth of human beings. The Swahili concept of *utu*, a Swahili mutation of *ubuntu*, means humanity, humanness, or full social inclusion. *Utu* emerged in the course of the abductive research process of this study as a moment of serendipity, a jubilant moment of research discovery (Timmermans & Tavory, 2022). The concept initially emerged from the data and was then used to make sense of the studied phenomena. It made me realize that the ethical and moral values of African communitarianism and Swahili philosophy are underexplored in the human rights literature and that the dominant disability models have very little interface with *utu*, which is central to the understanding of worth in the context of Tanzania, disability and female adolescence. The concept of *utu* inspired me to reflect, as did Onazi (2020), Imafidon (2021) and Nyamnjoh et al. (2021), on how African ethical and moral values could contribute

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[22] The participant used the term *mtu* (person) instead of *binadamu* (human).

to remedying cultural conceptions and perceptions of disability, such as those exemplified here:

> I will ask her [Nuru, the protagonist], 'do you live with your father and mother, do they love you or not' because sometimes parents don't love persons with disabilities, they don't accept them, and they harass them.
>
> Girl with albinism, aged 14, study participant

> About this issue of *utu*, I can say that it is something that has been inbuilt in our societies from the very beginning. For years and years, Africans have accorded a certain status to persons with disabilities. And those who are without disabilities, they are granted priority. There is some sort of disapproval.
>
> Woman with physical disabilities, member of the research advisory committee

I claim that *utu* as humanness has the potential and uniqueness to respond to human differences and to frame the discussion on and investigation of worth and social inclusion. It may have the potential to compel dialogues on sexual and reproductive health and the related entitlements in Tanzanian settings in which rights language is rejected, or to inspire social inclusion where the emancipatory political framework of the social model seems too much to ask of persons with disabilities on the outermost margins of society (see Katsui, 2012). Furthermore, *utu* has led me to wonder what the nature of sexual and reproductive health and rights discourse would look like in Tanzania in the context of the *utu*-driven understandings of belonging and personhood. I thus propose that *utu* entails the relational understanding of belonging called for by Reeves et al. (2022), that can make social inclusion relational, experiential, fluid and negotiated, and intimate and informal. These aspects may enrich our understanding of social inclusion and could encompass the realities of Tanzanian adolescent females with disabilities.

The conceptualizations of personhood in African communitarianism have been typically understood as reflecting a hierarchy of people and as excluding certain groups, such as women, children, or persons with disabilities (Chisale, 2018; Fay, 2016; Imafidon, 2021; Ngubane-Mokiwa, 2018; Nyamnjoh et al., 2021; Onazi, 2020). This implies that being born a human does not always automatically grant personhood, and that it is the community that grants or denies it (Ogude & Dyer, 2019). Someone who lacks humanness is understood as a *human* whereas a *person* is someone who portrays "truthfulness, respect, good manners, generosity, obedience, humility, attentiveness, love for people, relatives, friends, providing for those you are with to help raise their children well; all the good things done by a person (*mtu*), that is humanity (*utu*)."(Rettová, 2020, p. 36). *Utu* is loaded with moral content that encompasses the social constitution of humanity and personhood:

> Mtu ni watu ('[to be] a human being is [to be among] people') underscores the social characteristics of *utu*. *Utu ni kitendo* ('humanity is action') stresses the importance of manifesting *utu* through actions. And finally, *mtu si kitu* ('a human being is not a thing') means that the value of a human being is of a different kind that that of things and it is impossible to treat a human being like an instrument used to further one's own purposes. (Rettová, 2020, p. 37)

In addition to the distinction between a human and a person, according to the Swahili philosophy and the concept of *utu*, the value of a human being is of a different kind to that of things (Rettová, 2020). However, at times the treatment of adolescent females with disabilities portrays them as an instrument. An example of this moral culture was given by a man with albinism, a member of the research advisory committee:

> It is very true that a lot of people want to be with people with disabilities, not because they truly love them, but because of superstitious beliefs or just for kicks, that he slept with a girl with disabilities. There are still challenges in society, the fight to make sure that persons with disabilities are respected still has a long way to go.

The hierarchy of persons, the logic of inclusion and exclusion, and the level of autonomy is dependent on whether community is conceptualized in a broad (Gyekye, 2004) or a narrow sense (Menkiti, 1984). Many scholars have engaged in these debates and I follow here with the distinction made by Imafidon (2021) and Nyamnjoh et al. (2021) between the theorizations of the two scholars Gyekye (1987, 2004) and Menkiti (1984), which offer somewhat contrasting perspectives. The taxonomy of the two different views of community and personhood is provided in Table 11. The objective of this categorization is not to dichotomize or oversimplify the two perspectives, especially due to their fluidity as described below, but to support the theorizations later in this chapter in the discussion on the potential of these approaches to affirm worth and the community's obligations towards the sexual and reproductive health and rights of adolescent females with disabilities.

Table 11 Taxonomy of radical and moderate communitarianism

	Radical communitarianism (Menkiti, 1984)	**Moderate communitarianism (Gyekye, 1987, 2004)**
View of community	Narrow sense of community	Broad sense of community
	Supremacy of community	Supremacy of individual
	Community as a moral developer	Community as a bestower of moral worth
	Community plays a role in granting personhood	Community plays a role in actualizing personhood
	Collectivistic view of community: Community fully constitutes our being	Individualistic view of community: Community partially constitutes our being
	Limited recognition of autonomy	Room for autonomy and self-assertiveness
	Based on reciprocal obligations	Based on "asymmetrical obligations" (Onazi, 2020)
View of personhood	Processual	Static, one either is or is not a person
	"Personhood-as-acquired" (Nyamnjoh et al., 2021) if moral and contributory obligations are fulfilled	"Personhood-as-endowed" (Nyamnjoh et al., 2021)
	One can fail at personhood	Impossible to fail at personhood

	Granted on the basis of seniority; excludes children, granted on the basis of ability and contribution; excludes persons with severe intellectual disabilities or those with significant functional limitations	Granted on the basis of *potential* moral capability, regardless of whether or not potential is actualized
	Personhood as a social birth	Personhood as a physical birth
	No opening for persons with intellectual or severe disabilities	Opens personhood to those who have not conventionally been acknowledged as persons
	Personhood is entirely social	Personhood is social, yet one is also understood as a metaphysical being

Menkiti's (1984) (see also Etieyibo & Ikuenobe, 2020) narrow sense of community conceptualizes personhood as processual, something that can be acquired if moral and contributory obligations are fulfilled (Onazi, 2020). This view can also be described as radical communitarianism. According to Gyekye (2004), a broad sense of community depicts personhood as something one is granted, and considers that one either is or is not a person. Gyekye's view is also understood as individualistic or moderate communitarianism; community only partially constitutes our being and leaves room for individual autonomy. This allows, for instance, the freedom to step outside a community to evaluate and revise its interests and values (Nyamnjoh et al., 2021). In this broad view of community, personhood-as-granted depicts that everyone is morally capable, at least potentially, regardless of whether or not the potential is actualized (Nyamnjoh et al., 2021).

Menkiti's (1984) radical communitarianism conceptualizes personhood as processual, something that can be acquired if moral and contributory obligations are fulfilled (Onazi, 2020). One does not start out as a person but becomes one through moral development and the conditioning of the community (Imafidon, 2021). Community plays the role of a moral communicator and educator and in determining whether an individual can reach moral excellence and provide sufficient contributions to community life (Nyamnjoh et al., 2021). According to this view, personhood also has potentiality, as it suggests that it is also something at which one can succeed or fail.

The views of personhood based on radical communitarianism were more prevalent in the findings of this research. According to radical communitarianism, personhood is bestowed by seniority, social birth, and contribution, and thus produces oppressive relationships (Nyamnjoh et al., 2021). This is visible in how radical communitarianism may give minimal opportunities for personhood and worth to those with, for instance, severe intellectual disabilities or deaf persons (also in Onazi, 2020). The role that the type of disability plays in being granted personhood is demonstrated in the following:

> Humanness is the way others care for and look out for you. But the truth is that not everyone cares for other people, because when we talk about human dignity or being

> cared for, it depends on the condition of that person and what kind of disability they have.
>
> Deaf woman, member of the research advisory committee
>
> It [personhood] depends on the condition and type of the person with disabilities, but in short, a person without a disability is granted personhood, and respected more because they contribute to the community but a person with disability who has no job and no means of earning an income cannot be granted personhood because they are not contributing anything to the family, so they are not valued.
>
> Woman with physical disabilities, member of the research advisory committee

The aspect of contributing as a facilitator of personhood is central and can be further elaborated. Low expectations of the person being able to contribute on an equal basis with others leads to a vicious cycle: It may reinforce negative self-image and lead to further normalizing of negative perceptions of persons with disabilities, and reinforce passiveness (Katsui, 2005, pp. 90–91). Ableism perpetuated by neoliberalism and productivity (see neoliberal-ablism by Goodley, 2014, p. 34) seems to be intertwined with the social worlds and expectations of Tanzanian persons with disabilities, complicating the establishment of their worth. Furthermore, even if a person with disability could contribute, they may be denied the opportunity to do so, and in doing so denied an opening for personhood. This is elaborated in the following examples provided by a woman with physical disabilities:

> My father-in-law and mother-in-law do not treat me well because they know I have no job. Even if I complain about their son, they just tell me to persevere. Perhaps he has done me wrong, but they won't say anything to him, and they just take me for granted. So, that is denying me human dignity. There are also other places where I'll never be granted human dignity. For instance, my aunties, they never show me human dignity, the best they can do is talk and gossip. For instance, they never tell me when there are family parties, they would never directly tell me about these, until somebody else does. This is because they only have contempt for me. Show me no dignity at all. So, I usually say "thank you, 'a leaking bucket is a relief to its carrier'"[23]. It's better this way because they've prevented me from contributing the little bit I could have, as they didn't tell me. They didn't treat me with humanness.

Gyekye's (2004) broad view of community, personhood-as-granted, depicts that everyone is morally capable of reaching personhood at least potentially, regardless of whether or not the potential is actualized (Nyamnjoh et al., 2021). Unlike in radical communitarianism, in moderate communitarianism, personhood is bestowed during physiological birth, not during social birth, and this also bestows worth to those whose moral capabilities may be compromised (Onazi, 2020). This view of personhood on its own was less prevalent; my analysis showed that the projected understanding of personhood drew from both radical and moderate communitarianism. It took diverse shapes at the intersections of multiple identities and included notions of personhood as gendered and ableist. This is demonstrated below in how the opening of personhood was presented to anyone with diligence, however, the processual understanding of personhood, and the links to moral development on the basis of radical communitarianism are also present. For instance, a male with a physical disability, who is educated and lives in urban

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[23] Swahili proverb: *Kuvuja kwa pakacha nafuu kwa mchukuzi.*

settings enjoys certain levels of privilege compared to someone living in the outermost margins of society, and can readily agree that personhood is processual and open to persons with disabilities:

> I would say that someone with a disability can reach full social personhood because even myself, I've been able to do that. Therefore, I know that we can somehow reach that goal, and we can reach full personhood which will make society say that we can be depended on. There was a time when I travelled to help someone but it was obvious I couldn't do anything. But after putting my humanness into action, people saw that I had the ability to do so. So it is very possible for us [persons with disabilities] to reach full social personhood like other people.

Imafidon (2021) argues that the exclusionary conception of personhood in African communitarian philosophy should be counteracted with moderate African communitarianism, which offers a broad, inclusive view of community and opens up personhood for persons with diverse disabilities. However, this research has demonstrated that the concept of personhood and human worth is fluid and draws from both radical and moderate views. The concept of personhood in moderate communitarianism was distinct from that depicted in this dissertation, as the opening up of personhood to those who have not conventionally been acknowledged as persons could not be taken as granted. The findings demonstrated that the sexual and reproductive health entitlements of adolescent girls with disabilities, and their value and worth in the community were mostly not granted to them if their potential to contribute or to excel morally had not been actualized.

Based on the analysis of my collected data, I support Imafidon's (2021) view that the concept of personhood, when leaning towards the moderate communitarian perspective, has the potential to be used as a model to affirm the worth of adolescent females with disabilities. I also support the argument made by Nyamjoh et al. (2021) that both radical and moderate approaches could contribute to the revaluation of children with disabilities in African, and in this case Tanzanian, communities. As Nyamnjoh et al. (2021) posit, through its processual view, radical communitarianism demands continuous moral development, as it poses the "danger of rendering personhood meaningless if we are simply content with moral capacities as they are" (p. 11). This lifelong moral demand compels those in a position to care, protect and support to do so even if reciprocity cannot be expected (Chisale, 2018). This is particularly relevant in the case of persons with severe, multiple and intellectual disabilities. With regard to adolescent girls with disabilities and ensuring their sexual and reproductive health entitlements, we should understand the two perspectives, i.e., radical and moderate African communitarianism, as complementary, as possibly offering community accountability through asymmetrical obligations (Onazi, 2020), and as affirming inherent value and worth (Nyamnjoh et al., 2021; Onazi, 2020).

6.4 Belonging, social becoming, and sexual and reproductive health and rights

The findings of this research demonstrate that various social, economic, and personal entitlements flow from belongingness and contribute to advancing sexual and reproductive health and the related entitlements. The previous sections in this chapter have shown that belonging to a community is central to establishing the worth of persons with disabilities, but also that the denial of personhood may compromise human dignity and entitlements. In Tanzania, children and youth are conceptualized through the social maturation paradigm (Chataika & McKenzie, 2013) as adults in the making or as undergoing the process of becoming a full member of society (Fay, 2018; Uprichard, 2008, p. 303). According to this view, children are underdeveloped, and their moral and contributory capacity still grows and develops (Nyamnjoh et al., 2021). In this research, in line with radical communitarianism, the potentiality of personhood or social becoming was understood as mediating inclusion and exclusion on the basis of age, gender, and disability. Social conditioning and moral development was perceived as central to establishing the worth of adolescent females with disabilities, and *adhabu* (discipline) and the concept of *adabu* (respect, good manners) (see Fay, 2016; Stark, 2018) played a key role in this. The relation of *adabu* and *utu* to moral development is demonstrated in the following:

> *Utu* and *adabu* go hand in hand. One cannot have *utu* and lack *adabu*. If I have *adabu* then I definitely have *utu* because by practicing self-discipline I respect others, older and younger than me. I will also show acts of humanness to the young and old alike. So, these things go hand in hand.

This view of personhood having to be acquired by adolescent females with disabilities was present throughout the research. For instance, the contributory role was distracted by menstrual pain, and the shame and disavowal related to having sexual relations as an unmarried adolescent were understood as failing the social and gendered expectations of becoming a full social member of community, a member with worth.

> *Utu* and *adabu* can affect the life of a girl with disabilities because if she has no manners, people might not take care of her, they will despise her. Then there is a person who, when helped, never gives thanks because she lacks *utu* and *adabu*. So these two concepts, they go hand in hand, and can make a society perceive someone in a negative light.
>
> Man with albinism, member of the research advisory committee

> During our discussions, I have observed that *utu* is divided into two parts; the actual person and the people surrounding them and the way they are treated. But *adabu* involves the actual person, as in how they respects themselves. Do you follow the norms? How do you follow the norms? That means you might ask a child to come to you and then she comes slowly towards you. You might then say she has no manners, because how come she comes so slowly when called? So that is personal, but *utu*

> involves the actual person and the people that surround them, so that they might become humane and treat others kindly.
>
> Woman with physical disabilities, member of the research advisory committee

This dissertation has demonstrated, in accordance with Undie and Izugbara (2011), that sexual and reproductive health entitlements, whether related to services, information or protection, are activated through social relations. As regards sexual and reproductive health challenges, a deaf female member of the research advisory committee describes the role of the community in activating a sense of worth and space in which adolescent females with disabilities can express themselves:

> I'm still going back to the point made by others, that personhood depends on how a girl carries herself and the environment in which she was raised. Such an environment can make her feel uncomfortable, and even when she's not okay she won't say a thing because sometimes she's despised. I'm referring to the community around her by this. It's important to support her in order to build her ability to express herself whenever she has a problem.

Similarly to Fay's (2016, 2019) observations on child protection in Zanzibar, the community perceptions of sexual and reproductive health and rights entail views on social becoming. Fay (2019, p. 324) posits that rights, and based on my analysis I would add that sexual and reproductive rights in particular, are often perceived as a disruption to the cultural norms of social becoming. Sexual and reproductive health and rights are approached with reservation because they seem to exclusively reflect liberal and secular perspectives from the global North. This also reflects a larger phenomenon regarding the inability of human rights language to penetrate social and cultural beliefs, not just about sexuality and reproduction but also about disability (Onazi 2020). Such disruption of norms may have a countereffect on belonging and then in turn on the sexual and reproductive health entitlements that flow from that belonging.

How sexual and reproductive health and rights are understood depends on the position of the individual. In international development, it is currently understood through a policy sense of the term, yet I ask, what if it was understood in more relational terms that would expand it from formal and public to intimate and informal, from policy to the community realm. In sum, there is a need for dialogues on sexual and reproductive health and rights that go beyond a singular normative order of sexual and reproductive well-being, so that they reflect and respond to the Tanzanian context and the perspectives of adolescent females with disabilities without endangering the social becoming and belonging from which their entitlements flow.

6.5 Contributions of the dissertation

In this section, I present the three main contributions of this dissertation. The first is a theoretical contribution to the thesis of belonging. The second is a methodological contribution that is presented through the concept of relational epistemic safe spaces. The third contribution of the dissertation is to international development policy and practice, in which the implications of the belonging-based model and the concept of safe spaces are discussed against the backdrop of the globalizing trend of disability inclusion. Throughout this section, I draw from notions of belonging such as social inclusion, community, and personhood insofar as they relate to sexual and reproductive health and rights.

6.5.1 Towards a thesis of belonging

The first contribution is theoretical, based on the literature of disability models, especially the social model of human rights (Berghs et al., 2019), and on the notion of belonging in social inclusion (Reeves et al., 2022). This contribution draws on the Tanzanian intersections of disability and female adolescence, which call for a unique approach to disability that is inherently collectivistic, and takes into account the gendered norms of social becoming. In the process of gaining an in-depth understanding of the source of the sexual and reproductive health and well-being of adolescent girls with disabilities in communities, a member of the advisory committee, a man with physical disabilities, concluded:

> Rights are good. The convention [UN CRPD] provides us with a good model for changing laws and policy. But its implementation is a problem in our country. We need a contextualized model of implementation; we need to translate rights language into a language that any villager can understand. A new moral law.

As depicted above, the Tanzanian context underscores the need for a disability model that enables transcending from the formal (human rights), to the informal and intimate, and which applies language that can permeate cultural and moral values. This model could encapsulate a moral culture (Reinders, 2002), enacted through relationships, which would support the belonging of persons with disabilities and the entitlements that flow from belonging. As suggested by the research advisory committee member above, this model could act as a complementary model to the social model of human rights. It would enrich both the human rights model, essentially the model of disability policy, and the social model of disability, which at its core is a model of conceptualizing disability and emancipatory disability politics (Lawson & Beckett, 2021). It would do so by shifting social inclusion to relational and informal spaces where it could take the shape of something fluid and negotiated. Furthermore, it would be a model that draws from the African communitarianism, and be applicable at the community and familial level, as it uses the familiar terminology of humanness and belonging.

Thus, based on the empirical work in this study, I propose a complementary model that has the potential to enrich and re-invigorate the social model of human rights by reflecting the social conditions in Tanzania (see Levitt, 2017). I suggest a *belonging-based social model of human rights,* which draws from the perspectives of Tanzanian persons with disabilities and African communitarianism. It would be a stronger tool for social justice and entitlements, and not merely a model for disability policy (human rights model) nor a model for conceptualizing disability (social model). In essence, it would be a communitarian model that compels those in a position to care, support and protect to do so (radical communitarianism), while affirming the worth of all persons (moderate communitarianism).

This model is supported by empirical research that goes beyond this dissertation and argues that approaches to the social inclusion of persons with disabilities in collectivist contexts are personalistic rather than legalistic (Harry, 2020, p. 246), and thus the concept of belonging helps to encompass personal experiences and explain intimate and informal inclusion (Reeves et al., 2022). A complementary thesis is in order as the model's functions and the levels on which they operate are manyfold: The belonging-based model operates where moral reform is needed, the social model operates where policy reform is needed. The human rights model, in turn, identifies and addresses the gaps in policy. Complementarity is also needed because on one hand, the social model of human rights may underemphasize relationality, and on the other hand, on its own the belonging-based model may miss important opportunities for mobilization, social change, and realizing rights. These models and their different functions are further categorized and elaborated in Table 12. This categorization should be addressed with caution due to its complementary nature and the overlaps between the models.

Table 12 Social, human rights, and belonging-based models of disability

Social, human rights and belonging-based models of disability			
	Social model of disability (C. Barnes, 1998; Finkelstein, 1980; Oliver, 1983)	**Human rights model of disability (Quinn & Degener, 2002)**	**Belonging-based model of disability**
Function	A theoretical framework for understanding the process of disablement which defines disability as a form of social oppression (French, 1994; Lawson & Beckett, 2021)	A policy framework providing guidance and requirements for policy responses to disability (Lawson & Beckett, 2021)	A conceptual framework for human worth and moral culture in relation to disability
Goal	Equality, independence, autonomy, and choice for persons with disabilities, achieved by removing societal barriers	"Societies that are genuinely inclusive, societies that value difference and respect the dignity and equality of all human beings regardless of difference" (Quinn & Degener, 2002, p. 15)	Human engagement from which "asymmetrical obligations" (Onazi, 2020), worth and entitlements flow.

Based on	Claims of the emancipatory disability movement (UPIAS, 1976)	International human rights standards	African communitarianism
Cause of disability	Societal exclusion (Visagie, 2015)	Violation of rights (Katsui, 2012)	Denial of belonging to community and familial networks
Solution	Social change that challenges and eliminates disability (Lawson & Beckett, 2020; Katsui, 2012)	Disability policy and law reform in line with human rights principles and obligations, as set out in the UN CRPD (Lawson & Beckett, 2021)	Moral reform based on the moral imperative of those in a position to care, support, and protect to do so (radical communitarianism (Menkiti, 1984)), while affirming the worth of all persons (moderate communitarianism (Gyekye, 2004)).
Role of persons with disabilities	Active stakeholders and experts in all matters that affect them	Rights holders and duty bearers	Members of social networks
Responsibilities based on	Belonging to the political category of disability and the demands of the disability movement.	Belonging to the category of a legal citizen, in which demands are based on international and national legal obligations and accountability for realizing the rights of individuals (Katsui, 2012, p. 25)	Belonging to humanity. Asymmetrical obligations are compelled by collective moral development and duties governed by social and cultural norms.

The belonging-based model describes the ontology of disability through denial of belonging, as at its core is the relational understanding of personhood. It is also heuristic in the sense that it models a mechanism for identifying the disabling factors in the process of acquiring personhood. Barriers to belonging are dismantled through moral means. The belonging-based social model of human rights operates to enable the reorganization and refashioning of a community that affirms the worth of persons with disabilities. Like the social model of human rights, the responsibility for ensuring well-being and entitlements is placed outside the individual, on the community, in its role as moral educator and developer. The exclusionary social structures, attitudes and practices that deny belonging are addressed through moral, and at times asymmetrical, obligations towards others.

Unlike the social model of human rights, the belonging-based model does not suggest that marginalized individuals claim their rights or mobilize themselves on the basis of the emancipatory politics of social inclusion. It uses the understanding of human difference, which is inherent in the African understanding of humanity. Some scholars argue that dividing people into those with and those without disabilities is a global North originated binarizing construct (Rao & Kalyanpur, 2020). Community is thus seen as a social justice mechanism that has organically brought together people with a range of physical and mental traits, and vulnerability is seen as permeating human existence: "*mtu si lolote, si chochote, yaani hana thamani, hana udaima*" ("a human being is nothing, has no value, no lasting existence") (Rettová, 2020, p. 37).

Furthermore, the belonging-based model diverges from the social model of human rights, as it lacks motivation to form a social movement for persons with disabilities to advance the implementation of their particular human rights standards. This is not to say that this mobilization might not take place in the Tanzanian communities, but the question to be asked is whether the dualistic concept of disability and categories of able and disable are relevant as a driving force in the African communitarian philosophy and African disability justice. In other words, the belonging-based model is based on the argument that disability models that distinguish or set persons with disabilities apart from mainstream society may not be relevant in the Tanzanian context—what is needed is a model that allows weaving them tighter into the existing social fabric.

This is supported by the understanding gained in this research that it is not always disability that sets people apart from each other; at times it can be seniority, marriage status, or lack of contribution to community living. Thus, the belonging-based model focuses primarily on belonging to humanity, whereas the social model of human rights focuses on belonging to the political category of persons with disabilities. As disability theorizations will continue to co-exist and evolve in Tanzania, the thesis of belonging enriches the existing theories and provides a new analytical lens through which to explore inclusion and worth.

Persons with disabilities from all over the world are increasingly subject to economic hardship, climate change, displacement, migration, and other unforeseen challenges compounded by the existing inequalities. Furthermore, links to climate change and its negative implications for sexual and reproductive health and rights are well established (Chersich, 2019; Hardee & Mutunga, 2010; Stephenson et al., 2010; Tanyag, 2018; Torell et al., 2012). This is a global challenge, but many of the above hardships are rather new to countries in the global North, but African scholars have already been studying them for a long time (Comaroff & Comaroff, 2011; Swartz, 2014). While being mindful of contextual differences and the danger of romanticization or exoticization of Afrocentric theories, disability theorizations from the global South could be explored for their potential to also enrich disability theorizations in the global North, especially in regard to belonging and social inclusion. Introducing the Southern theories that are relevant to the majority of persons with disabilities in the world will gradually contribute to the disruption of the global North dominance of disability theorizations and shift the power imbalances of knowledge creation related to disability. It is this gradual change that I wish to contribute to with the thesis of belonging. In doing so, I am cautious of the othering that may emerge if the global North perspectives and academic progress on disability models are fully disregarded (Makhubela, 2016, p. 1), and thus have remained with a complementary thesis, which takes into account the relevance of the different models (Lawson & Beckett, 2021).

6.5.2 Safe in her story? The potential of relational epistemic safe spaces

The second contribution is methodological, from the literature of decolonial disability research methodologies (Adams, 2014; Grischow et al., 2021; Keikelame & Swartz, 2019; Seehawer, 2018), and participatory methodologies for socially and culturally sensitive topics (Amin et al., 2020; Dickson-Swift et al., 2007; Roegman et al., 2016; van der Heijden et al., 2019). This methodological journey has led to experiences and methodological developments in sexual and reproductive research on adolescents with disabilities in Tanzania and to the participatory disability research process. I first discuss the contributions to the notion of epistemic safe spaces, which are understood as a prerequisite for the pursuit of marginalized knowledges (Anderson, 2021), then I turn to discuss the role of the research advisory committee as a community that became both an agenda-setter and the agenda itself (Seehawer, 2018). To conclude, I frame the ultimate methodological contributions of this dissertation through the concept of *relational epistemic safe spaces*.

Features of the lives of Tanzanian adolescents with disabilities affect processes through which the knowledge for, on, and by them is gathered, judged and disseminated (Mji et al., 2011; Pincock & Jones, 2020; Scully, 2020). Epistemic injustice (Fricker, 2007) provides a platform for examining these processes. Epistemic injustice occurs when "someone is wronged in their capacity as a knower" (Fricker, 2013, p. 1317). It is sustained through refusal to develop or recognize ways of knowing that are different from the mainstream ways, which in turn maintain ignorance regarding the experiences of vast populations (Pohlhaus, 2012). Having one's accounts epistemically disregarded will most likely disown their own narratives and confidence in their overall capacity as knowers (Scully, 2020).

Safe space is a conceptual metaphor used to describe the conditions required to facilitate free expression among groups that are often silenced (Djohari et al., 2018; Pyndiah, 2018). Safe spaces have epistemic significance. They promote the *epistemic agency* of those at the margins of society (Anderson, 2021). Epistemic agency is understood as the capacity to contribute to the production of knowledge (Fricker, 2015; Miracchi, 2015). The term "epistemic safe space" was used in this study as a conceptual resource that enabled adolescent females with disabilities to move towards epistemic justice by applying lenses that recognize the different systems of oppression such as ableism, ageism, and colonialism (Anderson, 2021).

In this research, storytelling created a space that aligned with the norms of communal knowledge generation and enabled participants to practice their epistemic agency. Accommodating the method of empathy-based stories for participants with diverse capacities enabled increased participation in knowledge generation. Although I was only partly able to address ableism, colonialism, and ageism as systems of oppression in this study, paying attention to ableist assumptions, for instance, centered the perspectives of the studied adolescents to some extent through methodological choices. Even though the study was carefully planned and implemented to include adolescent females with intellectual disabilities, I was unable to accommodate those with severe intellectual disabilities, as many are confined to their homes. Including participants with mild and moderate intellectual disabilities was also a challenge as we lacked the skills and sustained presence that could have better facilitated our responses to their individual communication styles and preferences, such as non-spoken communication. I regret not mobilizing resources through which this study could have better contributed to their epistemic justice.

6.5.2.1 Research as a community or community as research?

This section expands on the description of the epistemic safe spaces that were cultivated through the choice and adaptation of the methods described in Chapter 4. I focus here on the participatory disability research process with the research advisory committee. In accordance with Seehawer (2018), I argue that a group of people with a common research goal and interest that distinguishes them from others can be identified as a community. Our research advisory committee certainly developed into a community over time as we spent so much time together and cultivated emotional and learning exchanges. The significance of community should thus not be reduced to a mere research method or technique. The relationships established in the course of this research contributed to the cultivation of an epistemic safe space, but also contributed to the sense of community of the research advisory committee. In an open-ended evaluation form from 2022, a research advisory committee member, a woman with physical disabilities, describes the role of the expertise and learning exchanges that she and other members brought into this community of knowledge creation through mutual respect:

> I am one of the women with disabilities who have participated in his research since the beginning as a member of the research committee. I am a person who has been around different places in schools, colleges and communities with people with disabilities. In the committee we have heard each other's opinions about reproductive health and the stigmatization of people with disabilities, and we have also been able to share with each other the types of violence that constantly occur in homes, on the streets and in schools. We have gathered and given feedback on the various research steps we have reached. We have shared and discussed them all and everyone's opinion in the committee is respected.

Community can serve as an agenda-setter for both research and social justice issues (Higgs, 2010). Moreover, epistemic safe spaces can create collective strength and strategies for emancipation (Pyndiah, 2018). The research advisory committee members discussed the different end-products of the study, which included advocacy tools for adolescents with disabilities and using the results of the study to establish a project on reproductive and menstrual health management for girls and women with disabilities. Such willingness to set an agenda for social action, whether on a personal, community, or societal level was a by-product of the study, as it was not initially action orientated or aiming for emancipation.

Community can also become the agenda itself (Seehawer, 2018). The experiences of disability that the research advisory committee members from different organizations of persons with disabilities shared promoted a certain solidarity among them. However, the marginalization of females with disabilities, those with intellectual disabilities, adolescents, and youths narrowed the representation of persons with disabilities in the disability movement and the research advisory committee. As organizations of persons with disabilities collaborate with various donors in the development sector and in research, the risk is that knowledge on, for, and by Tanzanian adolescent females with disabilities is controlled and excluded from epistemic resources.

According to Stringer (2007), in participatory methodologies, stakeholders can question their assumptions "as they rigorously explore and reflect on their situation together, they can repudiate social myths, misconceptions, and misrepresentations and formulate more constructive analyses of their situation" (p. 11). An example of such an analysis in which community itself became the agenda, was that of one of the leaders of SHIVYAWATA, who sometimes came to oversee the participatory process. He stated that this research activity had opened his eyes to the diversity within the disability movement. He described how organizations of persons with disabilities typically focused on the rights and needs of adults with disabilities. However, by focusing on issues related to gender and adolescence, the disability groups involved in the research advisory committee had engaged in solidarity towards the "serious issues affecting our girls", as he put it. Perhaps intentionally cultivating epistemic safe spaces within organizations of persons with disabilities will create opportunities to recondition the power imbalances within the disability movement itself.

6.5.2.2 Methodology of belonging

In this dissertation I have attempted to reconceptualize safe spaces in disability research from the Tanzanian perspective. Applying decolonial lenses is central for epistemic safe spaces, as these should be places that are free of colonial oppression (Anderson, 2021). What follows was inspired by the Swahili concept of *utu,* humanity or humanness, a concept rooted in African humanism and Swahili philosophy. I suggest using it as a basis for approaching epistemic safe spaces in African disability research on sexual and reproductive health and rights. Disability scholars are in a position to counteract the coloniality of knowledge by de- and reconceptualizing disability from the perspective of diverse cultures (Adams, 2014; M. C. Hall, 2019) and by engaging in marginalized perspectives to challenge oppression (Dirth & Adams, 2019). Thus, there is a call for a strengthened dialogue to develop innovative lines of inquiry in disability studies (Meekosha & Shuttleworth, 2017). In this vein, decolonial theorist Chilisa (2012) accentuates that research needs to "create space for inquiries based on relational realities" (p. 3).

These relational realities are framed here by the notion of *relational epistemic safe spaces,* which build on the analysis of experiences from this research. The notion is founded on the understanding that in research practice, the concept of belonging means more than participation, as through relationships, one belongs to the community. Belonging situates the researcher within the community and in relation to others. These relationships are likely to last after the study due to shared experiences, friendship, and collaborative learning (Seehawer, 2018). This demonstrates consideration and genuine interest in the other person rather than an instrumental approach to others. Relational epistemic safe spaces are a non-linear process of becoming through others. Navigating research relationships through belonging places real demands on researchers, current research practices, funding, and research institutions. This shows the opportunities and challenges of applying decolonial lenses, as they denaturalize the mainstream research practices that are typically portrayed as standard (Adams, 2014).

Relational epistemic safe spaces allow researchers to occupy multiple positions and utilize multi-layered experiences during the research, as long as this strengthens respectful and caring relationships and is based on mutual benefit (Grischow et al., 2021; Jakobsen, 2012; Seehawer, 2018). The simplistic binary insider and outsider roles of the researcher (Chhabra, 2020) continue to be questioned through the notion of belonging, as this acknowledges the researcher's evolving position in relation to the community, which is connected to reciprocity and contributions. By belonging, the researcher becomes intertwined with systems of obligation and interdependence that are not necessarily restricted to a certain timeframe, such as the timeframe of a PhD project. Being based in Tanzania certainly provided the opportunity to play down the outsider role in this research, which may not be possible during the short-term research visits that are typical for many researchers from the global North. This kind of belonging to social networks, which required sustained presence, was only possible by combining the positionalities of a mid-career international development professional, and a PhD candidate. Recognition and consideration of the research participants and collaborators is also an inherent part of relational epistemic safe spaces, because a researcher is a researcher through others:[24] through the participants, collaborators, their valued contributions of expertise and commitment, and other researchers and scholars from various disciplines— both current and past—who may have walked before, alongside, or after the researcher in the form of scholarly work.

Storytelling is about engaging our relational selves (Mucina, 2011). Relational epistemic safe spaces based on belonging may engage storytelling methods to enhance mutual reciprocity and interaction between the researcher and the

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[24] According to South African Anglican bishop Desmond Tutu, *ubuntu* is a belief that: "A person is a person through other persons."

participant. Preferring oral narratives over written ones can effectively move us away from the overrepresented role of the individual in Western research paradigms (Achebe, 1988; Gobo, 2011). As discussed before, contribution to community and family life has been acknowledged as an important aspect in the conceptualization of personhood in African disability research (Aldersey et al., 2014; Imafidon, 2021; Onazi, 2020). Therefore, contributing to a shared story may make that story a pathway to belonging. Becoming a storyteller and a part of a *shared* story may hold greater social meanings for adolescents with disabilities than could perhaps be anticipated.

The diversity of abilities and needs characterizes communities and (disability) research. Opportunities to contribute to storytelling in mutually reciprocal ways vary. Onazi's (2020) concept of asymmetrical obligations is derived from African humanism, as a path to African disability justice. By making a distinction between mutual reciprocity and asymmetrical obligations, Onazi (2020) claims that the "relational ideal of community in asymmetrical terms, entails obligations towards the practical, social and emotional dependence of human beings who are in the position to support and assist other human beings" (pp. 139–140). When the concept of asymmetrical obligations is translated into knowledge production, we understand that those in a position to encourage and enable others to exercise their voice safely are obligated to do so. Asymmetry in obligations, rather than mutual reciprocity, is justified for the relational conception of safe epistemic spaces because "when a community is dysfunctional due to epistemic marginalization, everyone's ability to share, understand, and debate ideas is diminished"(Anderson, 2021, p. 6).

To summarize, in research with and on persons with disabilities and sexual and reproductive health and rights-related topics in contexts that draw from African humanism: 1) relational epistemic safe spaces suggest a shift from the mainstream individualistic research practices; 2) in the relational epistemic safe spaces the researcher is a researcher only through others, which situates them within the systems of interdependence; 3) these spaces may embrace storytelling methods as a pathway for diverse participants to contribute; and 4) asymmetrical obligations are in place for those in a position to enable marginalized voices.

6.5.3 Disruptive and generative intersectionality for international development

The third contribution of the dissertation is to international development policy and practice, especially to the literature on the globalizing trend of disability inclusion in development practices (Bezzina, 2020; Katsui & Chalklen, 2020; Katsui & Mesiäislehto, 2022; Rao & Kalyanpur, 2020). Recently, disability in has become more visible in international development, and the rhetoric of disability inclusion has been demonstrated by, for instance, the SDGs paying attention to persons with disabilities, the introduction of the Disability Policy Marker by the Organisation for Economic Cooperation and Development's Development Assistance Committee (OECD-DAC, 2020), and the United Nations Disability Inclusion

Strategy (United Nations, 2019). Despite this significant momentum in disability inclusion in international development policy discourses, mainstreaming it into practices still requires massive attention (Katsui & Chalklen, 2020). This dissertation has demonstrated that the intersection of disability, gender, and adolescence unveils layers of intricacy that challenge what is known and how it can be known. I also argue that this intersection may compel the international development sector to look inward and outward at the power imbalances inherent in the industry.

This dissertation started by recognizing that adolescent sexual and reproductive health and rights are a critical area of social inclusion and development. And yet, international development has insufficiently addressed (Hameed et al., 2020), funded (Buller & Schulte, 2018) or contextually understood (Standing et al., 2011) this area, especially in ways that are relevant to adolescent females with disabilities. The *leaving no one behind* principle is a core tenet of the SDGs, but what this dissertation has demonstrated is that the paradigm change in sexual and reproductive health and rights, from population control to self-determination of reproductive choice, has not carried to all population groups, especially many of those who are marginalized by their societies and communities.

Many adolescent females with disabilities in Tanzania continue to face discrimination and violence when it comes to sexual and reproductive health and rights. Strategies have been developed and applied to put words into action by operationalizing the *leaving no one behind* imperative in sexual and reproductive health and rights. These include aligning social norms with adolescent sexual and reproductive health and rights (Buller & Schulte, 2018) and promoting community-based approaches, including community-based advocacy, to sexual and reproductive health and rights (Denno et al., 2015). However, strategies are still mainly framed through the narrow, individualistic framework of human rights, and the collective approach tends to remain marginalized in development policy and practice (Katsui & Mesiäislehto, 2022). Furthermore, "it [the global disability rights approach] needs critical self-reflection to examine whether the approach really fits the reality when it is used" (Katsui & Chalklen, 2020, p. 151). This dissertation has presented a belonging-based model of disability, which enriches the social model of human rights (Berghs et al., 2019) through the perspectives rooted in Tanzania. I now describe the implications of this model for development policy and practice. Then I propose some methodological measures for the development sector. Although the case here is Tanzania, the contributions presented may also be applicable in other parts of the global South.

6.5.3.1 Clashing views: Belonging-based approach as an intermediary

Resistance to the human rights agenda is real in countries like Tanzania (Fay, 2019; Undie & Izugbara, 2011), especially when it comes to adolescent sexual and reproductive health and rights (Bylund et al., 2020; Nyblade et al., 2017). In line with Fay (2019), what if, instead of understanding resistance as refusal, resistance could be understood as a negotiation or a means of making social norms explicit? This would mean opening up sexual and reproductive health and rights for discussion, based on the assumption that they mean different things to different people. The opportunities to dismantle the misconceptions of different views being in conflict with each other and about rights inhibiting social becoming (S. A. Kelly et al., 2022; Wessells, 2015) could be increased by engaging in local dialogues on acknowledging and respecting the differences in views on sexual and reproductive health and rights. Such dialogues would be critical for building a common understanding of how sexual and reproductive health and rights could support the social becoming and belonging of adolescent females with disabilities. This may lead to diverse disruptions of norms, which would illustrate that sexual and reproductive health and rights are not merely a malevolent policy instrument, but something that contribute to genuine inclusivity in communities. After all, as this dissertation has demonstrated, it is not only rights per se that can disrupt the norms of social becoming, but also the negative outcomes of sexual and reproductive health and rights, such as violence, unwanted pregnancies, and STIs.

Engaging in dialogues is important, as maintaining opposing or competing views of different ideologies might lead to culturally diverse good intentions towards adolescent females with disabilities being ignored. The implications of this dissertation are in line with the dangers of the strict, decontextualized stance related to the human rights agenda as presented by S. A. Kelly et al. (2022):

> Global actors and institutions must loosen the grip on specific imaginings and representations of the implementation of children's rights and protection ideals so that contextually relevant norms and mechanisms supporting the wellbeing and safety of children and families across diverse histories and geographies can evolve in the midst of on-going social change and global connections. (p. 10)

In this vein, Fay (2019) also noted that human rights-based child protection programs perpetuated a "feeling of subordination in regard to the capability of raising and protecting one's own children that was a common feature of the impact of protection programs"(p. 326). In a similar manner, in Tanzania, families with children with disabilities are often under the patronizing gaze of rights-based programs, as they are confronted about hiding their children with disabilities behind closed doors or in their backyards. However, this deed is rarely understood from the perspective that these parents, guardians, and caregivers are often denied belonging, as the community imposes disability-related stigma on them. Furthermore, this paternalistic oversight of caregivers, introduced by the UN CRC, is potentially harmful to the informal networks of care, as it may outsource the safeguarding to governments and actors in the international development spaces (Liebel, 2020, p. 170).

Another example from the development sector of how the human rights model has failed to capture everyday realities is that of Botswana, where the use of a white cane pointed a finger towards a blind woman's family, accusing them of not providing her with the mobility support she needs (Ingstad, 2007). Undoubtedly, in such a context, disability rights activism that is based on human rights standards for assistive devices can be counterproductive and harmful. Furthermore, in many rural areas where people are illiterate and the reach of organizations of persons with disabilities is limited or non-existent, legal protection of human rights becomes irrelevant (Bezzina, 2020). In a similar vein, sexual and reproductive health and rights were formulated in a certain context in which certain assumptions and claims regarding self-determination make sense. The self-determination of persons with disabilities makes sense as the social and human rights model is a global North-oriented concept linked to self-reliance and autonomy (Katsui & Chalklen, 2020). However, where individuals are primarily conceptualized through belonging to one or more groups, the issue of self-determination as empowerment may not be directly applicable or relevant.

Furthermore, in various contexts such as Tanzania and Burkina Faso, many persons with disabilities have internalized the medical approach to disability (Bezzina, 2020). This is often compounded by a society that provides rehabilitation, health and education services framed by the medical model of disability. Thus, when services are available, they are specialized services, which involve segregating persons with disabilities into institutions and centers. This disconnects them from their social and familial networks that facilitate inclusion (McConkey, 2007). As this dissertation has shown, social networks are important, because through them, persons with disabilities can contribute, but it is also through them that worth is established, and entitlements activated.

Although the role of community and social networks is clear, it has been suggested that the development industry should be cautious about using *community* as a development strategy, as it may perpetuate the assumption that communities in the global South lack forms of support for persons with disabilities and are merely waiting for interventions from the outside (Grech, 2011b). Instead of an instrumental approach to community, a more integral approach should be taken that enables drawing from the local knowledge about the role of community and the various networks of connection and analyzing their functions and how they mediate well-being and entitlements. All in all, what lies beneath is the lack of in-depth understanding of the role of community. This leads us back to the lack of recognition of the strength-based approach that draws from local understandings, family and community in the context of disability and development (Aldersey, 2012b; Rao & Kalyanpur, 2020).

The development sector could use its role to help strengthen the belonging of persons with disabilities in social and familiar networks as a pathway to social inclusion. The sector should invest in understanding internalized oppression and trauma as being the result of denied belonging, which affects the parents of children with disabilities and the children themselves and apply this knowledge in its practices. The root causes of hiding children, violence, refusing assistive devices, or access to life-saving services may not be fully recognized or addressed through the human rights model, as its language and conceptual tools lack the notions of belonging. However, some aspects of the human rights frameworks could also be harnessed for a stronger relational stance towards, for instance, the right to be included in the community (UN CRPD Article 19), and making *social well-being* an integral part of the definition of sexual and reproductive health

(United Nations, 2014; WHO, 2014), which is currently positioned alongside physical, mental, and emotional well-being. Discovering ways to enhance belonging could enable healing and reconciliation through and within the development practice. To reiterate, rather than facilitating only the domestication of the UN CRPD, the development sector could facilitate bottom-up development of local models of disability, which draw from the logic of inclusion, exclusion, and social becoming, as well as reflection of these models on policies.

There is increasing demand from within and outside the development industry to decolonize development as a way in which systemic change can address the power imbalances within the sector (Peace Direct, 2021). The belonging-based approach to disability in development programming in Tanzania could be understood as a pathway towards decolonizing development, as it could be used to address the existing massive power imbalances by making the terminology, knowledge, and practices rooted in Tanzania central. Approaches such as this could then create a basis for dialogue and mutually enhancing discourses on sexual and reproductive health and rights and disability. According to Goodley (2016) "disability might be desired as an opportunity for thinking about our relationships with one another in the world. Disability sparks moments of reflective wonder as disability troubles the normative, mundane patterns of everyday life" (p. 16). Disability might then inspire decolonial reflections on development practices and aid relationships, in the way it "standardizes, quantifies and organizes life" (Kafer, 2013, p. 27), and on the practices and tools used to advance sexual and reproductive health.

In sum, the belonging-based model suggests a shift away from individualistic development practices that are confined to the human rights-based approach to disability and development. This may have implications not only for *what* could be done, such as focusing on strengthening belonging to the community and to familial networks of persons with disabilities, but also for *how* it is done, as it calls for system-wide self-reflexivity. In the following, I suggest how the concept of epistemic safe spaces I introduced earlier could be used as a method to cultivate such reflexivity, in order to value, recognize, and address human differences in the development sector.

6.5.3.2 Unveiling gendered, ableist, and ageist assumptions in development policies and practices

The UN CRPD (Art. 4.3) stipulates that consultation with organizations of persons with disabilities, including children with disabilities, is a key factor in ensuring that policies and practices take into account the needs of persons with disabilities. This consultation is an established good practice for designing and implementing international development activities (OECD-DAC, 2020, p. 15) and has become widespread throughout the development sector. Guidance on stakeholder consultations with organizations of persons with disabilities is growing (e.g., Government of Canada, 2022; Ministry for Foreign Affairs of Finland, 2016; United Nations, 2021). As the participation of organizations of persons with disabilities is becoming a mainstream practice in the international development sector, increasing attention should be paid to power, access, voice, and the distribution of resources within these organizations (Bezzina, 2020; Katsui & Chalklen, 2020). The danger is that the consultations continue to elicit homogeneous voices through narrow representation of persons with disabilities, based on tokenistic notions of participation. This dissertation has discussed the power dynamics within the Tanzanian disability movement that continue to render persons with intellectual disabilities and adolescent females with disabilities invisible in decision-making. An intersectional approach should be rigorously applied to recognize that persons with disabilities are heterogenous, and to examine the oppression of particular groups of persons with disabilities within disability movements.

Under the methodological contributions of the dissertation in Section 6.5.2, epistemic safe spaces were considered a conceptual metaphor for describing the conditions required to facilitate free expression in groups that are often silenced (Djohari, Pyndiah, and Arnone 2018; Pyndiah 2018). Epistemic safe spaces refer to experiential spaces (Stengel and Weems 2010), spaces free of oppression by dominant people, ideologies, or beliefs (Flensner and Von der Lippe 2019), and spaces in which lived realities can be revealed without social criticism and self-censorship (Boostrom 1998). Development practices are increasingly using safe spaces, understood in concrete and abstract terms, as a tool for facilitating the recognition of and addressing the oppression experienced by people who have suffered discrimination or violence, without causing them further harm (Megevand & Marchesini, 2020). They can also be understood as a way to operationalize intersectionality and the *leaving no one behind* imperative in development practices (e.g., UN Women & United Nations Partnership for the Rights of Persons with Disabilities [UNPRPD], 2022). I suggest that the development sector, especially the spaces at different levels at which sexual and reproductive health and rights are discussed, could greatly benefit from the notion of epistemic safe spaces.

In this vein, the concept of epistemic safe spaces requires development practitioners, donors, and non-governmental organizations to scrutinize the systems of oppression in which they operate. Intentionally cultivating safe spaces at the nexus of development and disability requires consideration of the intersecting social dynamics of age, gender, and disability that often place adolescents with disabilities in the margins of society (Pincock and Jones 2020; Anderson 2021). In line with Nieminen's (2022, para. 1) observations in the context of higher education, I suggest ableism and ageism as the framework to be used in the development sector to unveil how development practices are predominantly designed for ideal, able participants. Such frameworks may also help people recognize how adolescent females with disabilities continue to be framed as the Other through practices that foster narrow views of bodies and minds.

6.5.3.2.1 Ableist assumptions of voice

In an attempt to diversify the representation of persons with disabilities in international development, sensitivity to recognizing structural ableism within the industry should be increased. Critical views have suggested that the machinery of international development is calibrated by neoliberal ideologies that favor effectiveness and efficiency (Katsui & Chalklen, 2020). The effects of such neoliberalism have been identified in contexts such as the disability movement in Burkina Faso. As Bezzina (2020) has noted, the introduction of market economies and the colonial implications of normalcy push unproductive individuals to the margins of society, and to the margins of the disability movement. Emphasis on competition and productivity, embedded in results-based management, which is a common tool in the development sector, is not in line with the local realities and diverse abilities. Thus, many practices in the development sector place burdens on persons with disabilities, but also exclude them from grassroots strategic decision-making (Katsui, 2012). Kafer's (2013) concept of "crip time" may also apply to development practice: "rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds' and offers new imaginings for how we standardise, quantify, and organise life" (p. 27).[25]

Scrutiny of the development sector, as guided by the notion of safe spaces, reveals that certain methods and forms of communication are favored over others. Sometimes expectations and measures of competence are normalized (Facca et al., 2020), for instance, in the form of PowerPoint presentations, correct email etiquette, and access to high-speed internet, and are inflicted on the participants engaging in stakeholder consultations, workshops, interviews, and dialogues. Often, these methods and forms of communication are embedded in the structures of the development practices and are decided upon by development practitioners, many of whom are adults without disabilities. Furthermore, these practices are based on expectations of results in a given, typically tight timeframe. Ableist assumptions of literacy or having a mother tongue, which some marginalized deaf women lack are another aspect that may affect how well persons with disabilities, especially the most marginalized voices, can be given room in development practices (Katsui & Chalklen, 2020). Even the common practices of giving presentations and hosting dialogues in an audible manner reveal ableist assumptions of voice. This restricts freedom of expression for deaf participants in safe spaces. For instance, in her ethnographical study of deaf communities in Tanzania, Lee (2012), found that deaf spaces are permanent or temporary places where signing is the norm, fostering freedom of expression for the Deaf in Tanzania.

The expert-oriented development sector may also assume certain levels of education, which becomes another barrier for participation. Furthermore, access to ICT remains a distant wish or is unheard of, especially for marginalized adolescents with disabilities in rural areas. Many of the methods applied in

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[25] According to Baril (2016), *crip time* can mean three things: extra time to perform a task, a dominant understanding that this extra time is wasted, or an analytical tool to understand flexible temporalities as opposed to fixed ones.

development practices are also ableist, as they usually require writing, which may be stigmatizing to some less educated and illiterate participants, as well as to those with disabilities. Also, from the perspective of adolescents, school-related equipment, such as pencils and papers may bring school spaces, with their unique power relations, into the development spaces (Fay, 2018), and furthermore, privilege the written voice. Alternative means of enabling voice and documentation should be used whenever possible, but we should remain cautious of the inaccessibility of various participatory rural appraisal techniques used by development professionals, such as the Venn diagram (Adebo, 2000), empty jar exercise (R. Appiah, 2020), and seasonal timelines and calendars (Narayanasamy, 2022).

Engaging with adolescent females with intellectual disabilities in particular may provide the disruption of ableist practices needed in the development sector. It has been established that persons with intellectual disabilities can make meaningful contributions when they have an appropriate platform of interaction (Brown et al., 2018; Bunning et al., 2017; Flynn, 2019; Grove, 2022). Engaging with the non-verbal voices of individuals requires understanding the modes of communication and the preferred ways of interacting, which are only built over time through sustained presence (Davis & Watson, 2017). This must happen without all diagnoses being considered one and the same, and individual experiences and capacities being neglected (Mietola et al., 2017). It certainly challenges current development practices, especially if aspiring to meaningful participation that is more than just a *tick-the-box* type of cosmetic participation through mere presence. Thus, to ensure meaningful participation, we need to consider engaging with new modes and techniques of participation, ones that are not merely effectiveness- and efficiency-informed, neoliberal approaches to development work.

When it comes to safe spaces in development practices for adolescent females with intellectual disabilities, generative aspects could be introduced by thinking about dissemination of information (Rix et al., 2021) and informed and voluntary consent to participate in activities (Ho et al., 2018), and by including these perspectives in agenda-setting and decision-making (B. Kelly et al., 2000). Moreover, in the case of Burkina Faso, the role of relationships was noteworthy in the lives of persons with intellectual disabilities, namely those with caregivers. Without them, persons with disabilities had difficulties directly engaging in development practices (Bezzina, 2020). The layers of relationships, especially important for persons with intellectual disabilities, call for understanding the relational nature of epistemic safe spaces in development practices, and not only in academic research practices.

When delving into these considerations and engaging in new modes and techniques, ideally together with adolescent females with intellectual disabilities, new inclusive practices are most likely to emerge if development professionals are willing to bear some discomfort. The profound inequalities that have been evidenced (Fulton et al., 2021; E. Hall, 2010; Strnadová & Nind, 2020), also those concerning the sexual and reproductive health and rights of persons with intellectual disabilities (Björnsdóttir et al., 2017; Meer & Combrinck, 2015; Tilley et al., 2012), render the pledge of *leaving no one behind* meaningless and powerless in development practices and policies if the voices of adolescent females with intellectual disabilities are not invested in through new inclusive and relational practices. This may indeed become the ultimate test for measuring whether the inclusivity of the development sector is genuine, especially when it comes to advancing sexual and reproductive health and rights.

6.5.3.2.2 Ageism and the gendered assumptions of voice

To enable epistemic safe spaces for participation, ageism should also be recognized in the development industry. Ageism may look very different depending on the context, but in Tanzania, for instance, seniority typically grants more opportunities to voice one's opinions. Development politics are embedded in adult assumptions of adolescence and impose adult-made categories of age (Pincock & Jones, 2020; Sanders & Munford, 2017). The dangers of assuming the comparative heterogeneity of adolescents has been addressed in the sexual and reproductive health and rights discourse by separating adolescents into younger (aged 10–14) and older (aged 15–19) adolescents. However, to promote the participation and freedom of expression of adolescent females with disabilities in international development spaces, the categorizations of adolescence could be revisited and contextualized.

As this research has demonstrated, contextual differences, including sociocultural norms, affect the way in which different periods of life, such as adolescence, are perceived. I suggest that contextualized categories and definitions other than age could also be explored to generate age-responsive practices in the development sector that also consider disability and gender. Moreover, careful attention should be paid to intergenerational relations when eliciting the voice and participation of adolescent females with disabilities (Facca et al., 2020). Development professionals who are adults, particularly in contexts in which seniority of age is perceived as a privilege, should explicitly foster reflexivity. Furthermore, gendered assumptions are central to the participation of adolescent females with disabilities, as they usually place women and girls at a disadvantage (Momsen, 2020). In the case of Tanzania, men dominate politics and the economy, thus it is assumed that women and girls take the backseat in decision-making (McCleary-Sills et al., 2013; Schwab et al., 2019).

I have discussed epistemic safe spaces as a conceptual resource that could enable a move towards addressing the power imbalances within the development sector. I have underlined the limitations and restrictions that ableist, ageist, and gendered assumptions place on the participation of adolescent females with disabilities in development practices and in the disability movements that collaborate closely with development actors. Many of these assumptions are based on the positionalities of the individual development professionals. Intentionally cultivating epistemic safe spaces for freedom of expression in the development sector also requires a thorough inward look and openness to discuss gendered, ableist, and ageist approaches and to learn from failures. Making such assumptions explicit through individuals' reflexive practices may benefit the development sector, as awareness of the underlying assumptions increases. Without awareness and recognition, such assumptions cannot be addressed.

As this dissertation has illustrated, the existing approaches to disability and development in the context of Tanzania could be enriched by the belonging-based approach, which not only takes local realities, social contexts and cultural aspects into consideration, but is built on local knowledge about them. The international development sector should allocate programmatic resources and policy priority to the development of mechanisms which ensure rich marginalized perspectives, especially when it comes to the sexual and reproductive health and rights of adolescent females with disabilities.

6.6 Conclusions

In this section, I present the conclusions of the dissertation and summarize the contributions it makes. These conclusions are based on the fact that Tanzania is committed to the international human rights frameworks governing the rights of adolescent females with disabilities to sexual and reproductive health. Despite the potential of the human rights model of disability, this dissertation argues that the human rights framework is insufficient for framing the perceptions of adolescent females with disabilities of their sexual and reproductive health and rights in Tanzania.

First, the study has illustrated that the knowledge on disability generated in the Tanzanian context can enrich the existing models of disability. The study has also shown that the human rights model is challenged by resistance to human rights in communities, especially to adolescent sexual and reproductive health and rights, which are perceived as disrupting the norms of social becoming. The intersection of disability and adolescence adds another layer of intricacy to social becoming, which is based on expectations of productivity and contribution, respect, self-discipline, and at times pain denial. This dissertation posits that the notion of belonging is key to understanding how collective dynamics and informal networks of care function to fill in the gaps in sexual and reproductive health service provision, and to protect against violence. Various social, economic, and personal entitlements flow from belonging and contribute to the realization of sexual and reproductive health and rights. Thus, in line with a complementary thesis (Lawson & Beckett, 2021), the contribution of this study is that it enriches the existing social model of human rights by introducing a belonging-based model, which aims for a moral reform and complements the human rights model, which aims for policy reform (Berghs et al., 2019), and the social model of disability, which, among other things, is a model for determining disabling barriers and social change through emancipatory disability politics (C. Barnes, 2003; Oliver, 2013).

Second, this dissertation has demonstrated that adolescent females with disabilities face the potentiality of personhood in their social becoming of full social members of society (also in Fay, 2016). Disability, gender and adolescence mediate inclusion and exclusion. The study concurs with the views of Onazi (2020), Imafidon (2021) and Nyamnjoh et al. (2021) that the ethical and moral values of the African communitarian philosophy can contribute to remedying the cultural conceptions and perceptions of the intersection of disability and female adolescence. The dissertation has shown that the African communitarian concept of personhood is beneficial for understanding the socio-cultural, gendered processes related to adolescence and to establishing the worth of persons with disabilities. This is especially significant for establishing the worth and sexual and reproductive health and rights of adolescent females with disabilities in Tanzania. According to this processual view of personhood, the community and family members of adolescent females with disabilities are compelled by moral standards and asymmetrical obligations (Onazi, 2020) to ensure access to sexual and reproductive health and rights, regardless of the severity of the disability.

Third, the study has shown that the intersectionality of disability, gender and adolescence generates valuable knowledge for recognizing, addressing and rejecting the normalization of various aspects of unrealized sexual and reproductive health and rights. Such intersectional knowledge reveals the public and private oppressions related to sexual and reproductive health and rights and challenges the normalization of pain, inaccessibility, and obstetric violence. Moreover, it brings pluralism to the globalizing trend of disability inclusion by introducing the need to think in more relational and collectivist terms about sexual and reproductive health and rights, as opposed to thinking in individualized terms. This dissertation has furthermore demonstrated that the intersection of disability, gender and adolescence unveils layers of intricacy that challenge what is known and how it can be known. When generating this knowledge and in development policies and practices, researchers and practitioners could cultivate relational safe epistemic spaces that could help shift the power imbalances in disability research and international development. Full participation in research and in international development, as stipulated by the UN CRPD’s Articles 3, 29 and 30, calls for recognizing and addressing individualist, gendered, ableist, and ageist assumptions of voice.

To conclude, I claim that an in-depth understanding of human differences, community, belonginess, and personhood that draws from African communitarianism may not only gradually begin to shift the imbalances inherent in producing knowledge about disability and in the international development sector but may also be of value for humanity today. In this vein, the crisis of social isolation prevalent in many parts of the global North (Samuel, 2022) may benefit from Southern theories that build on belonging and social connectedness without taking human differences for granted. In addition, learning about belonging may also be beneficial for preparing and responding to the complex and unforeseen future of humanity in the global South and North, as recent world events have demonstrated. The timeliness—or timelessness—of the belonging-based approach may be illuminated by the following case from Herson, Ukraine. In the midst of the destruction of the River Dnepr's waterpower plant, leading to the disruption of the distribution of thermal power and water, the residents of an apartment building remarked: "Under these circumstances, one can only survive by helping neighbors whom we would previously have greeted only in passing in the yard"(Helsingin Sanomat, 2022).

6.7 Ideas for further research

Enriching the theoretical and conceptual work on belonging presented in this dissertation, as well as by other scholars of disability and development studies, calls for research t continues to build on the notion of belonging in Tanzania and beyond. Such research could ask how belonging is shaped or supported by the intersections of different identities and across different disability types. How could understanding belonging as social inclusion advance the aims of the disability movement in Tanzania? In the context of development policy and practice, it would also be important to investigate the opportunities that the belonging-based approach may offer programmatic interventions related to the inclusion of persons with disabilities. The development of evidence-informed belonging-based tools for development practices could also be explored. Also, building on this dissertation, how the belonging-based approach could be applied to help shift power imbalances in development research, practice and discourse cold be investigated. Finally, I suggest that future research could consider applying the framework of the belonging-based model to further unveil the aspects pertinent to enabling adolescent females with disabilities to access sexual and reproductive health and rights, based on their lived experiences.

According to this study and the existing evidence, many adolescents with intellectual disabilities are located at the outermost margins of their societies and are often excluded from research. Keeping in mind the heterogeneity and diverse capacities of adolescent females with intellectual disabilities (Mietola et al., 2017), it would be important to understand exactly what the relational constraints and enablers of their sexual and reproductive health and rights are in Tanzania and beyond. In this vein, there is an urgent need to develop and evaluate research design and methodological approaches that can be used to capture these individuals' views and to build an in-depth understanding of their sense of belonging. Building on the work by disability studies scholars on the concepts of belonging for persons with intellectual disabilities in the global North and South (Bannink Mbazzi et al., 2020; Fulton et al., 2021; E. Hall, 2010; Mahar et al., 2013; Reeves et al., 2022; Strnadová et al., 2018; Strnadová & Nind, 2020), it is particularly important that real-life experiences of belonging are explored in order to render visible the roles and meanings attributed to the different relationships from which entitlements flow.

Finally, there is scarcity of interventions that advance the sexual and reproductive health and rights of persons with disabilities and limited evidence on what interventions actually work in global South settings (Hameed et al., 2020). As disability inclusion gathers momentum as a globalized development agenda, more interventions are expected in the area of sexual and reproductive health and rights. I suggest that rigorous scientific studies conducted on this topic, which evaluate interventions, should not be confined to the narrow framework of human rights but entail a more nuanced understanding of rights and entitlements based on the notion of belonging, as advanced by this dissertation. This would contribute to the creation of reliable, contextually relevant social change theories and intervention models for the sexual and reproductive health and rights of persons with disabilities, to end the reliance on theories and models from the global North which may not only be ill-fitting, but at times even counterproductive.

SUMMARY IN FINNISH

Vammaisuuden ja kestävän kehityksen risteyskohta on noussut akateemisen huomion ja kehityspoliittisen kiinnostuksen kohteeksi Yhdistyneiden Kansakuntien (YK) vammaisten henkilöiden oikeuksien yleissopimuksen (2006) voimaantulon ja vammaisinkluusion globalisaation myötä. Vammaisten henkilöiden ihmisoikeuksien edistäminen seksuaali- ja lisääntymisterveyden ja -oikeuksien osalta on kasvava tutkimusala sekä vammais- että kehitystutkimuksessa, ja sillä nähdään olevan YK:n kestävän kehityksen tasa-arvotavoitteiden kannalta merkitystä. Suomea pidetään suunnantäyttäjänä vammaisten henkilöiden seksuaali- ja lisääntymisterveyden ja -oikeuksien edistämisessä maailmalla.

Tämä Tansaniaan sijoittuva väitöskirjatutkimus pohtii vammaisuutta kehityskysymyksenä seksuaali- ja lisääntymisterveyden ja -oikeuksien kautta. Erityisesti se keskittyy vammaisuuden, sukupuolen ja iän tuottamiin moninkertaisiin yhteiskunnallisiin marginaaleihin. Tutkimus tarkastelee intersektionaalisen tiedon tuottamisen mahdollisuuksia vammaisten tyttöjen seksuaali- ja lisääntymisterveyden ja -oikeuksien edistämiselle ympäristössä, jossa näihin oikeuksiin liittyy erityisen paljon kulttuurisia ja ideologisia ristiriitoja.

Tutkimuksessa vammaisuus määritellään kansainvälisenä kehityskysymyksenä, jonka ymmärtämiseksi tutkimus nojaa vammaisuuden teorioihin, erityisesti vammaisuuden sosiaaliseen ja ihmisoikeusmalliin sekä vammaisten henkilöiden seksuaali- ja lisääntymisterveyttä ja -oikeuksia määritteleviin kansainvälisiin sopimuksiin. Vammaisuus käsitteellistetään ilmiönä, jossa intersektionaalinen syrjintä ja globaalin etelän konteksti asettavat omat haasteensa ihmisoikeuksien toteutumiselle. Intersektionaalisuus käsitteenä mahdollistaa tutkimuksessa vammaisuuden ilmiön moniulotteisen ja kontekstuaalisen tarkastelun.

Vammaisuuden, sukupuolen, iän ja seksuaali- ja lisääntymisterveyden käsitteellistämisessä tutkimus hyödyntää aikaisempia tutkimuksia, joissa ihmisoikeusmallia pidetään riittämättömänä kuvaamaan vammaisuuden ilmiötä globaalin etelän konteksteissa. Se nähdään usein puutteellisena edistämään kestävän kehityksen tavoitteita maailman vammaisten henkilöiden enemmistön keskuudessa, joka asuu globaalissa etelässä. Näitä teorioita ja käsitteitä yhdistäen tämän tutkimuksen teoreettinen lähestymistapa määrittelee vammaisuuden yksilön vamman ja ympäristön välisenä vuorovaikutuksena, mikä usein asettaa vammaiset henkilöt eriarvoiseen asemaan suhteessa muihin.

Tutkimus kysyy, miten vammaisten tyttöjen näkökulmat kuvaavat seksuaali- ja lisääntymisterveyttä ja -oikeuksia kannattelevia ja rajoittavia tekijöitä; miten poissulkeminen ja yhteenkuuluvuus näyttäytyvät näiden oikeuksien näkökulmasta; ja millaisia edellytyksiä vammaisuuteen, nuoruuteen ja sukupuoleen perustuvalla intersektionaalisella tiedolla voi olla seksuaali- ja lisääntymisterveyden ja -oikeuksien edistämisessä. Tutkimus keskittyy tarkastelemaan erityisesti näkemyksiä palvelujen saavutettavuudesta, tyttöihin kohdistuvasta väkivallasta ja kuukautisterveydestä.

Tutkimuskysymyksiin etsittiin vastauksia laadullisen abduktiivisen tutkimusotteen ja osallistavan vammaistutkimuksen avulla. Tutkimus toteutettiin yhteistyössä tansanialaisen vammaisjärjestöjen kattojärjestön kanssa valtion viidellä eri hallinnollisella alueella 13 tutkimuskohteessa. Tutkimukseen osallistui 199 tansanialaista eritavoin vammaista tyttöä. Empiirisessä tutkimuksessa käytettiin eläytymismenetelmää ja analysoitiin eläytymistarina-aineistoa sekä osallistavan tutkimusprosessin kautta tuotettuja ryhmäkeskusteluja. Lähestymistapa mahdollisti vammaisten tyttöjen intersektionaalisten, kontekstuaalisten ja yhteisödynamiikkaa tarkastelevien näkökulmien tutkimisen Tansaniassa.

Kolmessa alkuperäisjulkaisussa raportoidut tulokset osoittavat, että vammaisten tyttöjen seksuaali- ja lisääntymisterveyden ja -oikeuksien toteutuminen perustuu inhimillisyydestä kumpuavaan osallisuuteen ja yhteenkuuluvuuteen. Sille on luonteenomaista epäviralliset perhe- ja yhteisöverkostot, jotka sekä kannattelevat että rajoittavat seksuaali- ja lisääntymisterveyden ja -oikeuksien toteutumista. Lisäksi yhteenkuuluvuuteen vaikuttaa vammaisten tyttöjen kohdalla käsitys sosiaaliseksi persoonaksi tulemisen epävarmuudesta, jota määrittävät yhteisöissä vallitsevat vammaisuuteen, sukupuoleen ja ikään liittyvät sosiaaliset normit. Vammaisuuden, iän ja sukupuolen perusteella tapahtuvalla sosiaalisella ulossulkemisella on näin ollen haitallisia vaikutuksia tyttöjen seksuaali- ja lisääntymisterveyden ja -oikeuksien toteutumiselle.

Tutkimuksessa ihmisoikeuksiin perustuva kapea ymmärrys seksuaali- ja lisääntymisterveydestä sekä huono seksuaali- ja lisääntymisterveys nähtiin esteenä sukupuolinormien mukaiselle sosiaaliselle kehitykselle ja näin ollen yhteenkuuluvuudelle ja osallisuudelle. Edellä mainitut tekijät ovat omiaan luomaan haitallisen kierteen, jossa yhteenkuuluvuus vammaisia tyttöjä kannatteleviin epävirallisiin turvaverkkoihin voi vaarantua. Tutkimus viittaa siihen, että afrikkalainen kommunitarianismi on hyödyllinen teoreettinen lähestymistapa vammaisten tyttöjen ihmisarvon sekä seksuaali- ja lisääntymisterveyttä edistävien moraalisten velvoitteiden uudelleenmäärittämisessä.

Vammaisuuden ja Tansanian kontekstin erityisymmärryksen pohjalta tutkimus argumentoi, että ihmisoikeusmalli ei ole riittävän monipuolinen viitekehys vammaisten tyttöjen seksuaali- ja lisääntymisterveyttä ja -oikeuksia koskevien näkökulmien tarkasteluun. Globaalin pohjoisen konteksteista nousevan ihmisoikeusmallin yksilökeskeisyys ei sellaisenaan sovellu kuvaamaan tansanialaisten vammaisten tyttöjen käsityksiä etuuksista ja velvollisuuksista, jotka pääosin rakentuvat vastavuoroisesti ja epäsymmetrisesti ihmissuhteiden kautta.

Tutkimuksella on kolme empiiriseen tutkimukseen perustuvaa pääkontribuutiota. Ensiksi se rikastuttaa olemassa olevia vammaisuuden teoreettisia malleja kehittelemällä yhteenkuuluvuuden käsitettä kuvaamaan monipuolisesti vammaisten tyttöjen asemaa suhteessa seksuaali- ja lisääntymisterveyteen. Se täydentää ihmisoikeusmallia vammaisuuden yhteenkuuluvuuden mallin kautta. Toiseksi tutkimus tekee metodologisen kontribuution esittelemällä yhteisöperustaisen episteemisen turvallisen tilan käsitteen episteemisen oikeudenmukaisuuden edistäjänä erityisesti silloin, kun tutkimuskohteena ovat marginalisoidut ryhmät ja kulttuurisesti sensitiiviset tutkimusaiheet. Lopuksi tutkimus ehdottaa huomion kiinnittämistä ableistisiin, yksilökeskeisiin, uuskolonialistisiin, sekä ikään ja sukupuoleen perustuviin oletuksiin osallisuudesta ja äänestä globaalissa vammaisinkluusiossa sekä laajemmin kehityspolitiikassa ja sen työkaluissa.

Tutkimuskontribuutiot ovat ajankohtaisia vammaisinkluusion globalisoituessa. Kansainvälisessä kehityspolitiikassa ja -käytännöissä painotetaan kasvavassa määrin vammaisten henkilöiden osallisuutta ja intersektionaalisten näkökulmien tärkeyttä. Tutkimus vahvistaa vammaisten tyttöjen äänen kuulumista kestävän kehityksen tavoitteiden edistämisessä seksuaali- ja lisääntymisterveyden ja -oikeuksien suhteen niin Tansaniassa kuin laajemminkin.

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ORIGINAL PUBLICATIONS

I

DISPARITIES IN ACCESSING SEXUAL AND REPRODUCTIVE HEALTH SERVICES AT THE INTERSECTION OF DISABILITY AND FEMALE ADOLESCENCE IN TANZANIA

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Article

Disparities in Accessing Sexual and Reproductive Health Services at the Intersection of Disability and Female Adolescence in Tanzania

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Abstract: Despite at times having greater needs for sexual and reproductive health (SRH) services, adolescents with disabilities often face challenges when trying to access them. This inaccessibility is further exacerbated during female adolescence. The qualitative study examines how SRH services respond to the characteristics of Tanzanian adolescent females with disabilities. We used the method of empathy-based stories to investigate the perceptions of 136 adolescent females with disabilities of their access to SRH services in Tanzania. The study used thematic content analysis and the Levesque model of health care access was applied as an analytical framework. The results demonstrate that discrimination affects access at different phases of care-seeking, that affectionate behaviour of providers is a central enabler of access, and that for this population access relies on a collective effort. We propose that affection, as an enabler of access, is as an additional provider dimension of access to SRH services for adolescents with disabilities, serving as a "reasonable accommodation" to the health care systems in southern contexts and beyond.

Keywords: sexual and reproductive health services; adolescence; disability; Tanzania; access to health care; inequality; SRHR

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1. Introduction

Adolescents with disabilities are as likely to be sexually active as their peers without disabilities and have equal rights to sexual and reproductive health (SRH) services [1]. Adolescence (ages 10–19) is a decisive time in a person's life during which significant physical, mental, and emotional changes take place [2]. Adolescents with disabilities have unique, and at times greater needs for SRH services but they often face challenges accessing them, especially in many African contexts [3–6]. These greater SRH needs often result from a lack of information on sexual and reproductive health and rights (SRHR) [4]; sexual abuse and rape, which increases the likelihood of pregnancy [5]; being infected with HIV or sexually transmitted infections (STIs) [7]; and an over-arching stigma [8]. Most of these SRH needs and negative outcomes are exacerbated during female adolescence [3]. Access to SRH services is hindered by physical inaccessibility [9], communication barriers [10], negative attitudes of service providers [4], lack of confidentiality [4,11], costs [4], mistreatment [11], and an overall inadequacy of service delivery [3,4].

The United Republic of Tanzania (Tanzania) has the second youngest population in East Africa [12]. Twelve million of its 54 million citizens are adolescents, an age group expected to reach 30 million by 2050 [13]. Tanzania has one of the highest adolescent fertility rates in the world [14]. Adolescence in Tanzania is associated with a high frequency of child marriage [15], insufficient knowledge about STIs [16], and restricted access to SRH services [17]. Limited access increases the risk of, for example, unplanned pregnancy and

STIs among adolescents [18]. What adds to the urgency for SRH services is the socially normalised sexual exploitation of adolescents in Tanzania [19,20].

Of Tanzanian homes, 13.2% have at least one member with a disability [21]. Information on disability remains unreliable, incomprehensive, and incomplete, making the lived realities of persons with disabilities and of different disability sub-groups insufficiently documented [22]. Tanzania has demonstrated commitment to advancing disability rights by ratifying the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and by enacting national disability policies. However, these have not yet translated into notable gains for persons with disabilities. At the policy level, adolescents with disabilities in particular are hidden in the homogenous image of youth and children, and the unique ways in which female adolescence interacts with disability in access to SRH services is neglected [23,24].

The expanding adolescent population, the negative trend in adolescent fertility rates, and the general status of persons with disabilities in Tanzania makes the disparities in the access of adolescent females with disabilities to SRH services a timely and urgent concern. Substantive research has examined the access to SRH services of different sub-groups of adolescents in Tanzania [16,17,25–29]. However, there is a scarcity of disability- and SRHR-related studies from Tanzania [30]. More evidence on SRHR and better access to SRH services among adolescents with disabilities in Tanzania are needed in order to inform health policies and implementation [31,32].

Research has predominantly portrayed girls and women with disabilities in African contexts through vulnerabilities, and little is known about their agency in terms of SRHR [33,34]. Greater engagement of adolescent females with disabilities with their SRH can be positively associated with the utilisation and effectiveness of services [3], and thus the factors influencing their agency need to be better understood. Consequently, this study employed a definition of access to health care that sees access as a result of "the interface between the characteristics of persons, households, social and physical environments and the characteristics of health systems' organisations and providers" [35] (p. 6). This broad understanding of access concurs with the CRPD definition that sees disability as an "interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" [36].

Recently, the Levesque health care access model [35] has proven beneficial in research on access to SRH services for persons with disabilities [37]. The model recognises the agency and capabilities of socially marginalised people rather than reinforcing a view of them as passive recipients [38,39]. It also allows looking at the variations in the access of different populations, to enable a better understanding of health care disparities [35]. The framework entails the relevant access-related concerns of persons with disabilities, such as accommodation and appropriateness [36,40]. The model captures five service provider dimensions: (1) Approachability, (2) Acceptability, (3) Availability and Accommodation, (4) Affordability, and (5) Appropriateness; and five service user dimensions: (1) Ability to perceive, (2) Ability to seek, (3) Ability to reach, (4) Ability to pay, and (5) Ability to engage. This article uses the analytical framework of the Levesque model of health care access to examine how different dimensions generate service users' access to SRH services or their disparity in accessing them. The objective of this study was to increase the understanding of access to SRH services of adolescent females with disabilities in Tanzania. The study aimed to answer the following research questions: How adolescent females with disabilities perceive the accessibility of SRH services? What characterises their capabilities to access SRH services?

2. Materials and Methods

A qualitative participatory research methodology was utilised to explore access to SRH services. The participants were 136 female Tanzanian adolescents with disabilities, aged 10 to 19. The average age of the participants was 15.5 years. The majority of the participants had hearing impairments (n = 42); one of them also had a physical disability. Others had physical impairment(s) (n = 33) and albinism (n = 32), and of these some (n = 11) also had partial visual impairments. In addition, the participants had intellectual impairments (n = 13), visual impairments (n = 12), and partial visual impairments (n = 4). Purposive sampling was used to identify the participants from a sampling frame established together with the Tanzania Federation of Disabled People's Organizations. Research was conducted in 13 locations across three regions in mainland Tanzania, mostly in school settings.

This research draws from data consisting of 257 empathy-based stories (EBS) that were on average 902 characters long, produced by the 136 participants. EBS are fictional short stories narrated by study participants as a response to a frame story [41,42]. The verbally collected stories were transcribed verbatim by the interviewer immediately after the interviews. The transcripts were translated from Kiswahili into English and cross-checked by a member of the research advisory committee and the researcher to ensure the quality of the data. This committee consisted of members of the Tanzania Federation of Disabled People's Organizations to ensure that the persons with disabilities played an active role in the study. The research advisory committee was pivotal in developing a culturally appropriate methodology, providing insights at the analysis phase and engaging in discussion on the results. In addition, the research advisory committee was instrumental for ensuring the validity of the study. By triangulating data from multiple sources, namely, empathy-based stories and research advisory committee proceedings, the in-depth interpretation of the data was enhanced.

The method of empathy-based stories (MEBS) was employed to acquire perspectives rooted in the participants' narratives. MEBS is grounded in constructivist and relativist epistemologies, where reality is understood as contextually and socially constructed [41]. MEBS assumes that the reality and narrative both reflect and imitate each other and the ability of the narratives to reflect personal meanings is more important than capturing lived experiences [43]. Thus, the focus in MEBS is not on researching lived experiences, but perceptions. MEBS is considered an ethically sensitive data collection method, as it allows participants to distance themselves from controversial and sensitive topics [43]. In addition, although the frame stories evoke perspective-taking that may lead to the activation of participants' personal experiences, they may decide whether or not they wish to disclose these.

EBS were narrated by the participants as a response to the short fictional frame stories provided by the researcher. The frame stories, as well as the visual and audio aids accompanying them, were developed with the research advisory committee and piloted prior to the data collection. Considering the unique characteristics of the participants, and their educational status, the participants took part in the storytelling verbally or in writing. The verbal storytelling sessions resembled individual interviews, in which the participants first responded to the frame story. After this it was possible to acquire more insights regarding their views through predetermined prompt questions. All participants were given the opportunity to respond to both frame stories. It would have been ethically problematic if some participants only responded to the negative variation of the frame story. The verbal data collection sessions were conducted in Kiswahili and in Tanzanian sign language.

The frame stories were constructed around two protagonists: Fatuma and Nuru. They reflected two common issues that require adolescent females to seek SRH services in Tanzania [29]. The frame story variation was constructed to simulate perceptions on the accessibility and inaccessibility of SRH services. The stories utilised were as follows:

> *Fatuma John is an 18-year-old girl with disabilities and she is pregnant. She needs to attend the health clinic. After visiting the clinic, she feels happy and safe. Tell us what happened at the clinic that made her feel happy.*
>
> *Nuru Hassan is a 15-year-old girl with disabilities. Nuru has a disease in her private parts and she is experiencing discomfort. She needs to see the doctor. In the meeting with the health professional something goes terribly wrong. Afterwards Nuru is really upset.*

> *Tell us what happened when she met the health professional. Tell us what disturbed her so much.*

Ethical considerations informed the design and methodology of the study. This was especially important as the studied adolescents are often made vulnerable by multiple discrimination in the society. Ethical concerns were also related to the culturally sensitive topic of SRH services. Accessibility to the locations and the methods and materials were carefully considered. Efforts were made to create safe research spaces that would ensure and promote physical and psychological safety as well as freedom of expression. Information sessions were held with participants and their guardians on the research sites. These sessions included information about the research aims and the storytelling sessions, confidentiality and anonymity, and the right to decline and withdraw from the study at any time. After ensuring a genuinely informed consent through an "explain-back" protocol, a written consent was received from participants and their guardians. For those that are illiterate, or with intellectual, visual, or hearing impairments, information and consent procedures were made accessible by using visual aids and by providing an option to give consent through an audio recording or by using a thumbprint. Processual view of consent was maintained throughout the study, and the participants were reminded in the beginning of their storytelling sessions about the voluntary nature of the study and the right to withdraw from the study at any time. Body language and ease of the participants was observed and documented. A storytelling session would be ended in case a participant portrayed discomfort. Ethical clearance for this study was obtained from the National Institute of Medical Research in Tanzania

The study used data-driven thematic content analysis. The researcher first closely examined the notions of accessibility and inaccessibility within the data by separating the story variations. Then recurrent patterns and topics were freely coded. The codes began to resemble dimensions of access in the Levesque model of health care access [35]. The appropriateness of the dimensions was discussed with the research advisory committee, as were the proposed codes under each dimension. Based on this triangulation of data with the research advisory committee, the thematic locations of the codes were refined and thematised under the Levesque model's dimensions of access.

3. Results

The findings demonstrated that, according to the participants' perspectives, the SRH services did not respond well to the characteristics of the adolescent females with disabilities in terms of Approachability, Acceptability, Availability and Accommodation, Affordability, and Appropriateness. Moreover, the provider characteristics had adverse effects on the service users' abilities to access services. In this chapter, we first elaborate on supportive networks and access, second on the social acceptability of the service users, third on the interpersonal characteristics of the providers, and finally on violence inside and outside the health facilities.

3.1. "Go and Bring Your Mother, So We Can Talk to Her": Supportive Networks and Access

The ability to seek health care is often associated with personal autonomy regarding seeking care and the capacity to choose health care options [35]. The findings of this study demonstrated that theorisation regarding access that emphasises self-determination is not always compatible with the lived realities of the studied adolescents in the Tanzanian context. Overall, the narratives did not present independence and self-sufficiency in a positive light. When such independence was demonstrated, it resulted in poor service-seeking outcomes. The narratives showed that for adolescent females with disabilities, seeking care is not an individual's decision; it is influenced by relationships and collective decision-making. The participants' stories also depicted a gap in the reasonable accommodation of services regarding their disability. For instance, there were no mention of formal assistance provided at the health facilities. Much of this gap was filled by relying on support networks, concurring with previous literature [4]. The role of supportive relationships has previously been associated with positive health care outcomes for persons with disabilities [44]. Various relationships can determine the ability to seek care, hence either restricting or enhancing access to care. Such relationships in this study were those between the studied adolescents and family members, teachers, matrons, community members (e.g., neighbours), other patients, and health care professionals. Good relationships with the surrounding community and family members were perceived to enable access. Support was largely described as enabling, but as it was based on benevolence and not fully reliable, as demonstrated below:

> *I told them [my parents] I can't go to the hospital alone. I told my dad and mum and they said 'Aah, we will take you later'. I decided to go to the nurse, I explained the situation to her, I asked her to help me. [. . .] She looked for the medicine and gave it to me. She helped me and I went home. So, she listened to me and helped me. I fell asleep but kept thinking 'Why am I alone? I have problems but no one to help me'. I met with my friend and told her. I met with another one and asked her to help me. So, she is now helping me.*
>
> Participant with hearing impairment, aged 19

There was a strong reliance on supportive networks in terms of finances, mobility support, communication, and safeguarding. Generally, the narratives portrayed households with low incomes, and health insurance was considered very rare. A collective effort was needed to mobilise funds to access SRH services, a process which was not always streamlined. Inability to pay was related to the autonomy and decision-making linked with choosing to seek care and make decisions about one's care. Although parents were usually responsible for health care payments, it was common that financial resources needed to be mobilised within the household and the community. Mobilising financial resources was at times portrayed as a time- and energy-consuming responsibility of the adolescent. The narratives also depicted that despite various efforts, sometimes they were in vain, and thus services or parts of the service were denied.

For those with physical and visual impairments, the main reason for needing an escort was the physical journey. For the studied adolescents with albinism, the need for assistance was related to superstitious beliefs regarding violence against persons with albinism. The service users needed support to reach the facilities, and the service providers often did not respond well to their ways of communication. Self-expression was hindered by a lack of the right terminology to explain, feelings of shame, and Kiswahili- or sign language-related barriers. Communication was not only a challenge for those with hearing impairments.

According to Burke et al. [4], the most common way to overcome communication barriers was by employing the assistance of a family member or using writing as an alternative means of communication. However, being accompanied by assistants and using writing were at times seen as problematic. The former jeopardised the privacy of the service users and the latter excluded those who were illiterate.

> *She [Nuru] went to the doctor but no one took care of her. When she tried to explain her need, nobody understood her. They were, like, 'aha!'. They examined her but they were, like, 'Hmmm? We can't help you with this, this is very serious'. So, she was afraid, very ashamed. So, the doctor told her 'Go and bring your mother, so we can talk to her'. Because of the way they were mistreating her she went to get her mother and explained to her: 'Mother please forgive me, I have this infection and it is not good at all, I am in a lot of pain. Let's go to the hospital'. Her mother helped her and went to the hospital. She went to the hospital to find the doctor who was mistreating her.*
>
> Participant with hearing impairment, aged 16

Arranging assistance was not always effortless. Shame related to the need for SRH care was sometimes perceived as the major barrier to requesting support. For those who were students, an escort was often provided by the school but for out-of-school adolescents it was disproportionately more difficult to arrange an escort. When assistance was not available, it was common to remain at home, which delayed access or made it altogether impossible.

> *[. . .] just because someone has a disability it does not mean that there are people who are always ready to accompany them all the time. You find a girl with a physical disability crawling on the floor, she starts to think about how to get out of the house and get to the hospital, that is more than a challenge. When she starts thinking of someone to take her to the hospital, she just gives up. Now it depends on one's illness, what it is like or when she got it because there is not always someone there to help you when you are in trouble. So, the issue of distance is a challenge and also finding someone to escort you.*
>
> Research advisory committee member with physical disabilities

Although supporting relationships are an essential enabler of access, previous studies have shown that they often compromise the privacy and confidentiality of the service users [40]. SRH needs were portrayed by the participants as a private issue; however, sometimes they had to rely on whoever was available to accompany them. Reliance on financial assistance in particular was perceived to challenge confidentiality and privacy.

> *For girls like these, they have no other place to get money, so she will have to tell her parents because she has no money. She can't do anything at all. For example, for those of us who are blind, it is difficult, because in everything that you do you need a helper, hence there will be someone who'll know what is going on even if you have your own money. The issue here is how will you go there? There is no way to hide. Even if you have an abortion you can't say the secret has remained between you and the doctor. Never! So for us there is absolutely no way to hide.*
>
> Research advisory committee member with visual impairment

3.2. "It Would Be a Great Idea If God Took Me": Social Acceptability of Service Users

The findings concurred with previous research on the general adolescent population in Tanzania, in that the participants did not perceive themselves as clients of SRH services, as if they were socialised to believe that the services were only for those who are pregnant and married [16]. Some narratives also portrayed uncertainty of whether a girl with disabilities could or should have children or could get married at all, which would restrict their access even further and negatively affect their social status in the future. Firstly, various social and cultural factors determined the perceived appropriateness of the studied adolescents seeking care. Secondly, social and cultural factors related to sex and pregnancy influenced how the participants accepted features of the SRH services.

SRH service acceptability highlighted the intersecting social categories that discriminate adolescent females with disabilities in complex ways when seeking access. In the participants' narratives, disability intersected with the following social categories: age, pregnancy, marital status, educational status, and impairment type. For instance, when disability compounded with age and pregnancy, further discriminatory aspects were demonstrated by the participants:

> *A normal person is warmly welcomed, they even help with handbags but if they see a pregnant person with disabilities, they start giving her unsolicited advice. They give her medicine then tell her 'You can just go home'. So, she goes home, takes the medicine and waits for her due date, as it is still early for delivery. Other persons with disabilities feel like they are wasting time going back and forth to the hospital. This is because first and foremost she is pregnant, as well as a person with disabilities, and for this reason it is not good to go to the hospital earlier than on her due date.*
>
> Participant with hearing impairment, aged 19

Compounded by the above, a certain impairment type may have a negative effect on how the studied adolescents are perceived as SRH care-seekers. When a hearing impairment or albinism co-existed with adolescence, acceptance of the adolescent was especially hindered. In contrast, being married and/or having at least a basic level of education increased the acceptability of disability.

The service providers, family members, and even other patients were engaged in this discriminatory behaviour.

> *When seated at the bench with other patients, they might start talking badly about me saying things like 'Look at this child! She's an albino. She's disabled. Look at how her eyes stick out!' [. . .] Other patients might say 'Look at those eyes! They're bulging!' So, they can say these things that make me feel bad and make me not want to go to the hospital. I find myself in despair and start thinking it would be a great idea if God took me.*
>
> Participant with albinism and visual impairment, aged 12

The participants' narratives demonstrated that it is perceived as forbidden for adolescent females with disabilities to engage in sexual activities. These negative and judgmental attitudes towards sexual activity influenced how acceptable it was for them to seek SRH services. The consequences of risky sexual behaviour, pregnancy, and STIs were also highly condemned by the girls themselves and their communities. This judgmental attitude towards sexual activity was presented as a protective mechanism placed on the studied adolescents by their communities. As such, it was partly accepted by the studied adolescents. However, it was also perceived as a limitation to their relationships, to the extent that they were instructed to avoid any social contact with boys and men. Unlike many studies that highlight how the surrounding society assumes persons with disabilities to be asexual [33], the participants' narratives included no such notions. On the contrary, the narratives embedded a view that they were perceived by their communities to be sexually active because of their disability and age.

If pregnancy were perceived as socially acceptable, seeking services would also be perceived acceptable. However, the social acceptance of pregnancy was determined by marital status, age, disability type, education, frequency of pregnancy, poverty, and how the pregnancy was initiated (e.g., in a relationship or through rape). Marriage, higher age, education, and infrequent pregnancy were factors that increased the studied adolescents' acceptability to seek SRH services. Regardless of many external factors, some of the adolescents' narratives still indicated an internalised view of themselves as unacceptable clients.

A participant with a hearing impairment, aged 14, gives advice to Fatuma. Her account illustrates how advantage and disadvantage co-occurs with pregnancy and disability. Such dynamics were prevalent in the narratives.

> *I would tell her if that is the case [being pregnant] then there's nothing you can do about it. Because if she aborts, she could also die. She can kill the unborn baby, but she can also die. I would advise her to persevere until she gives birth as she's not alone in this. There are others who are also persons with disabilities and pregnant. She's lucky because she's pregnant and is still able to go to the hospital. There are others who are too afraid and stay home.*
>
> Participant with hearing impairment, aged 14

3.3. *"They Should Show Love, Caring and Kindness": Interpersonal Characteristics of the Providers*

Shame, among other negative emotions regarding the need for health care, was portrayed as restricting the ability to seek care. The interpersonal qualities of the providers did not respond well to such negative emotions. Their attitudes towards the studied adolescents were reflected in patient blaming, neglect, refusing to treat, laughing at, verbally insulting, yelling, and openly despising the condition of the person or their disability. These findings are aligned with those of Burke et al. [4], which indicated that poor service provider attitudes are barriers to SRH access among young persons with disabilities.

The narratives highlighted the absence of being attended to as person first, rather than disability first. The impairments were shown to supersede the need for SRH. The participants described how service providers perceived disability as a strong label even when it shadowed the actual service needs.

> *When you go to the doctor, people with disabilities are despised. So that everyone is comfortable, they should all be treated equally so as to avoid asking 'Doesn't she hear at all?' 'Can't she speak at all?'. Doctors should give medical care according to the patients' needs.*
>
> Participant with hearing impairment, aged 17

In addition, the SRH condition of the service user could also become such a strong label that she is no longer treated person first but as the manifestation of an illness or a health condition.

The participants vividly narrated what would be the ideal characteristics of an SRH service provider. Demonstrating affection was the most prevalent description.

> *As a person with a disability, my advice to doctors is [that] they should know that when you scold and criticise a person with disabilities, she won't be at peace. Therefore, they should show love, caring and kindness.*
>
> Participant with physical disabilities, aged 15

Demonstrating affection included giving a warm welcome, using kind and encouraging words, giving positive feedback, having the ability to listen and explain well, taking affirmative action towards persons with disabilities, and assuring the continuity of the services.

3.4. "I Don't Want Your Money; I Want Something Else": Violence within and Outside Health Facilities

The findings demonstrate that SRH services appear to reflect the social dynamics prevalent in society, including sexual violence and exploitation of adolescents and women with disabilities [20,45–47]. The narratives entailed gross depictions of the studied population exposed to transactional sex and sexual exploitation as a result of the aforementioned financial dependency and the desire for privacy in SRH services. The narratives described how demanding sexual favours in exchange for care was embedded in society.

> *There is financial corruption and sexual corruption. [. . .] So, I advise him [the doctor] to avoid such things. Should he engage in such activities he will be violating his work ethics and also disrespecting himself.*
>
> Participant with albinism, aged 14

> *The specialist told her: 'The cost of my help is too high, I don't know if you can manage it'. Nuru told him: 'If it's the money you want, just tell me how much so that I can ask for help from my relatives and friends'. The doctor replied, 'I don't want your money, I want something else'. Then the girl was devastated and started crying.*
>
> Participant with physical disabilities, aged 15

There is evidence that sexual violence by health providers occurs worldwide [47] yet a secrecy surrounds sexual misconduct in medicine, making it difficult to identify cases [48]. These findings concur with other studies, which indicate that, in SRH services, for those who are perceived as deviant of social norms, abuse is more common [47]. The findings are also in line with previous literature, in that the female gender [48] and considerable power disparities between the health provider and the service user may combine to generate sexual violence in health care settings [49]. Here, adolescent females with disabilities were seen as not conforming to the social norm of an SRH service user due to their disabilities, age, and other intersecting factors, which could be contributing factors to sexual violence. The narratives included notions of a lack of confidence when in the company of the service provider, which may denote a power distance between the adolescent females with disabilities and the health care providers. Female health providers were preferred over males due to the fear of males requesting sexual favours and even of sexual violence.

> *Participant: She the [female doctor] will remove your clothes and I don't want a man to see me naked. [. . .] Male doctors have really bad behaviour.*

> *Researcher: What kind of bad behaviour do they have?*
>
> *Participant: Having sex with patients.*
>
> Participant with intellectual impairment, aged 19

There were references to sexual violence and exploitation by health providers even without association with payment. Depictions of sexual advances indicated the presence of sexual violence among the participants' lived realities within and outside health care settings.

> *There are some doctors who are just crazy. You go to the hospital expecting to be treated but he starts doing other things instead of treating you. He starts telling you strange things. You get out of there angry and frustrated because you went there to seek medical treatment and not to be asked strange, silly questions or to be seduced.*
>
> Participant with hearing impairment, aged 14

In addition to the violence within health care settings influencing access, the ability to engage in one's care is also further restricted by sexual violence towards the studied participants within society. The evidence that violence prevents engagement in health care by persons with disabilities is consistent with findings of other studies [50].

4. Discussion

The unique role of relationships in the disparities of SRH access of adolescent females with disabilities in Tanzania cuts across the principal findings. Here we further discuss the role of relationships, first by looking at the relationship between the service user and provider, and secondly, by focusing on patients as members of collective entities. Finally, we elaborate on the relationship between the service providers and their environments. From there, we move on to the role of affection in these relationships.

A negative relationship with service providers makes SRH services an extension to the stigma, neglect, and abuse so often faced outside health facilities by the studied adolescents [20,45]. SRH service access disparities were perceived to be generated by the unprofessional behaviour and discriminating attitudes of the service providers towards the studied adolescents. SRH services' failure to treat patients respectfully concurs with other studies from Tanzania [51,52]. Disability embodiment appeared to further reinforce disrespect. Although the service users portrayed high expectations of psychosocial support from SRH services, the services in turn were perceived to offer them neglect, insults, and abuse, often leading to a perceived countereffect on their well-being. There is strong evidence that affectionate communication increases positive health care outcomes [53], and good interpersonal skills have proven to positively influence the utilisation of services [54]. Thus, the service providers play a pivotal role in increasing the quality of care and positive health outcomes. Their interpersonal skills could perhaps be developed without an undue burden on the Tanzanian health system by adopting simple techniques of affectionate communication into their encounters with service users. This is indeed good news for the Tanzanian health care system, whose resources are scarce and other aspects of SRH services may be costly and hard to change. In the relationship between the service users and providers, disturbingly, sexual violence appeared to negatively influence access. Considering the limited opportunities of the adolescents to express themselves in the study, their epistemic standpoint becomes important when drawing conclusions about sexual violence in the context of SRH services. The often-silenced views of this population need to be listened to, taken seriously, and further explored to overcome the violence and overall disparities in SRH care access.

The current study has presented adolescent females with disabilities as part of collective entities: families, communities, and informal networks of care. It shows that the family and community largely determine SRH access and that these relationships are in turn determinants of access disparities. This collective approach to disability, which sees disability as a family or a community concern rather than an individual's concern, is still marginalised in disability theorisations [55]. Nevertheless, Aldersay [56] has developed a Tanzanian approach to family and disability, which argues that building on existing strengths of families and communities is a more sustainable intervention strategy than focusing on their deficits. This strength-based view can be expanded further, as the findings support the understanding that in southern contexts "charity is a way of survival when no institutionalised support is available" [57] (p. 135). Traditionally, the charity approach and human rights discourse have been contradictory. This juxtaposition has been perceived problematic in disability research in the global South [57–59] as, for example, the well-being of persons with disabilities is largely dependent on charity [57]. This tension between the approaches could be used to recognise a continuum between charity and rights approaches. Such non-binary thinking is certainly a lesson to learn from the southern perspectives on disability [60,61].

Health care often reflects the social dynamics that are normalised in society overall [47], including the marginalisation of persons with disabilities and their families. To understand the SRH service providers amidst social forces, we need to turn our attention to the drivers of the injustices. Despite policy-level commitment to adolescent-friendly SRH services [26,62], the facilities that actually implement it are few [29]. The problematic implementation of adolescent SRH policies may result from the complex discursive SRHR landscape that spreads across the restrictive–liberal divide in Tanzania [63]. According to Bylund et al. [28], complexity in adolescent SRHR may be intensified by contradictory and inconsistent messages regarding SRHR policies, the legal framework for providing services to underaged adolescents; the president's personal views on SRHR; and community attitudes. The inequalities in the Tanzanian SRH services appear to be rooted into ageism, ableism, and patriarchy, which, according to the results of this study, intersect with disability and female adolescence, but also with marital status, poverty, STI status, social networks, and educational status. These intersections produce specific circumstances of power, disadvantage, and identity that differ from the lived realities of other adolescents. In accordance with the present findings, previous studies have also pointed out that SRH service providers navigate within a complex gendered environment, a moral framework in terms of premarital sexual activity, socio-cultural norms around marriage [64,65], and the diverse characteristics of service users. This ambiguous social and political environment provides SRH service providers with inadequate response mechanisms to the characteristics of the studied adolescents.

Affection is an overarching theme across SRHR research and within the relationships of persons with disabilities [57,66,67]. According to Shakespeare [68] (p. 3), "rights alone are not enough to promote the well-being of disabled people, and that charity—defined broadly as love and solidarity—must also play an important part". Charity, reconceptualised here as affection, is an indispensable part of disability in southern contexts in which the well-being of persons with disabilities is much dependent on it [57]. In the context of CRPD, reasonable accommodation, and access to SRH services, affection can also be understood as a pathway of "necessary and appropriate modification and adjustments", which will unlikely become an "undue burden" to systems, collective entities, and individuals [36]. As proposed by Katsui and Mesiäislehto [69], affection is a central aspect of the well-being of persons with disabilities and should be included as a principle in global disability inclusion. The present study raises the possibility that affection is also a central enabler of access to SRH services and is thus proposed as an additional provider dimension for the SRH services of adolescent females with disabilities in southern contexts and beyond.

This study had various limitations. The ethical and methodological choices of utilising MEBS means that the findings are based on perceptions rather than on real-life experiences. Recruiting participants mostly from school settings through an organisation of persons with disabilities may have resulted into exclusion of adolescent females with disabilities in the furthermost margins of the society. The participants may have shown social desirability bias when discussing sensitive and at times socially unacceptable behaviours and may not have narrated the stories without self-censorship. Thematically, from the broad scope of SRH services, the study was confined to exploring access to services related to adolescent pregnancy and STIs. The participatory and storytelling approaches provided an opportunity to minimise the power differences between the researcher and the participants. The triangulation of the results to the research advisory committee was an attempt to reduce any biases caused by the researcher's background and to strengthen the validity of the study.

5. Conclusions

This study is among the first to examine the inequalities faced by adolescent females with disabilities when attempting to access SRH services in Tanzania. The results show that the studied adolescents are capable of more engagement in their SRH service access, but that the characteristics of the providers and systems do not respond well to their characteristics. The findings of this study broadly support previous work that demonstrates the challenges when accessing SRH services [3–6], such as physical inaccessibility [9], communication barriers [10], negative attitudes of service providers [4], issues of confidentiality [4,11], and mistreatment [11]. Although this consistency with previous studies is an important achievement, the study also brought forth new insights into the intersection of disability and female adolescence with access to SRH services. The main findings were that various identities simultaneously produce advantages and disadvantages and that discrimination affects the access of these adolescents to SRH services at different phases of care-seeking. Moreover, the study revealed that service providers' affectionate interpersonal skills are a central enabler of access, and that access is a collective effort. It also showed that SRH services reflect the social dynamics of a society, including sexual violence against adolescent females with disabilities.

The findings of this study have several implications. In Tanzania, SRH-related policies and health care programmes should address the characteristics of this population and consider affection a reasonable accommodation to ensure equal access for adolescent females with disabilities to SRH services. These findings should be incorporated into the national adolescent-friendly SRH service response, as well as the National Plan of Action to End Violence against Women and Children. Safeguarding principles within health care should be emphasised, including transitions within, to, and from the facilities. Further research based on the experiences of this population is urgently needed to develop a full picture of sexual violence inside and outside health facilities, which can inform prevention. To contribute to this, the first author is in the process of writing a publication on sexual violence against the studied population. There is also abundant room for further progress in the methodologies used in southern disability research on the SRHR of adolescents. Future publications will use experiences from this study to elaborate on this.

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II

RETHINKING GENDER-BASED VIOLENCE AND ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH SERVICES THROUGH THE PERSPECTIVES OF TANZANIAN ADOLESCENT FEMALES WITH DISABILITIES

by

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In review

Rethinking gender-based violence and access to sexual and reproductive health services through the perspectives of Tanzanian adolescent females with disabilities

Adolescents' access to sexual and reproductive health (SRH) services is a critical development issue in Tanzania, yet the intersection of disability and female adolescence is compounded by barriers to SRH service access and socially normalised gender-based violence (GBV). Using the method of empathy-based stories (MEBS), I explored the perceptions of 136 Tanzanian adolescent females with disabilities of how GBV and access to SRH services are intertwined. The findings demonstrate that the intersection of disability and female adolescence within SRH services render invisible various forms of violence, which are not only gendered but also ableist and ageist. Recognising access to SRH services as a distinct site of violence and addressing the issue in relevant policies and programmes could strengthen the SRH of adolescent females with disabilities. The findings contribute to Southern disability theorisations that draw from collective dynamics in the rethinking of accessible and protected SRH services.

Keywords: sexual and reproductive health and rights, access to sexual and reproductive health services, gender-based violence, adolescence, disability, Tanzania

1. Introduction

Ensuring access to safe, accessible, and good quality adolescent sexual and reproductive health (SRH) services is critical for sustainable development (Starrs et al., 2018). The Sustainable Development Goals (SDG) target 3.7 calls for universal access to SRH services, and the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) stipulates obligations to make SRH services available to persons with disabilities on an equal basis with others (UN, 2006, art. 25). Moreover, the UN Committee on the Elimination of Discrimination against Women (CEDAW) general recommendation No. 35 states that 'abuse and mistreatment of women and girls seeking sexual and reproductive health information, goods and services, are forms of gender-based violence' (CEDAW, 2017, emphasis added). In this vein, addressing violence against adolescents, and improving adolescent SRH services have been identified as key priorities in sexual and reproductive health and rights (SRHR) research in Africa (Ali et al., 2018).

Despite ambitious international policy frameworks, the available evidence from African contexts demonstrates that although adolescents with disabilities have unique, and at times greater needs for SRH services, they often face challenges accessing them (Burke et al., 2017; Obasi et al., 2019; Rugoho and Maphosa, 2020). Furthermore, females with disabilities are at an increased risk of gender-based violence (GBV) (Bangura et al., 2021; Carew et al., 2017; Meer and Combrinck, 2015; Njelesani, 2018; Wudneh et al., 2022). Additionally, it has been established that in various contexts violence influences the access of persons with disabilities to SRH services (Mesiäislehto et al., 2021; Patel, 2017; Tilley et al., 2012; Wudneh et al., 2022).

The intersection of adolescence, gender and disability remains largely unexplored in Tanzania, and is limited to only a few studies (Mbwilo et al., 2010; Ngilangwa et al., 2016; Quinones et al., 2021; Sanga et al., 2022). Furthermore, as the GBV experienced by adolescents with disabilities in Tanzania remains largely unknown, recognition, prevention and addressing it is difficult. In Tanzania, adolescence is characterised by limited access to SRH services (Mchome et al., 2015; Nkata et al., 2019), and it has been suggested that negative adolescent SRH outcomes are exacerbated by disability (UNICEF, 2021). Furthermore, the standpoints of Tanzanian adolescent females in the context of accessing SRH services remain underrepresented in research as well as in a society that excludes the perspectives of this population from epistemic resources and results in decontextualised understandings of the links between access to SRH services and GBV.

This article is situated between the scholarly literature on disability and development (Grech and Soldatic, 2016; Katsui and Chalklen, 2020; Shakespeare, 2014), and the conceptual developments of violence within the context of SRH services (Chadwick, 2021; Lappeman and Swartz, 2021; Laverty and de Vos, 2022; Wudneh et al., 2022). Using empathy-based stories as a method to study the narratives of Tanzanian adolescent females with disabilities, the article explores the ways in which GBV is intertwined with access to SRH services. The topic is especially significant in the context of Tanzania, a country with multiple international and national commitments to SRHR of adolescent females with disabilities. Tanzania has an expanding adolescent population, which is expected to double by 2050 (United Republic of Tanzania, 2018). Thus, addressing adolescents´ SRHR in a way that reduces social inequalities will have an impact on the future of the nation (Neal et al., 2020).

This article is divided into six parts. First, I introduce the prevalent conceptualisations of disability, access to SRH services and GBV. Second, I present the structural factors specific to the Tanzanian context in terms of GBV in SRH services. Third, in the methods section I present practices of knowledge production, researcher positionality and ethical considerations. Fourth, I provide the results of the analysis. Fifth comes the discussion of the conceptual advancement following on from the results, and finally I conclude with limitations of this study and its implications for development and disability research, policy and practice.

2. Defining disability and gender-based violence

Disability is a multifaceted, complex phenomenon. It is a manifestation of human diversity that varies across different contexts (WHO and World Bank, 2011). According to the UN CRPD, disability results from the interaction between an individual’s impairment, and personal and environmental factors (UN, 2006). In this article I draw from the CRPD's definition of disability and employ the intersectional understanding of disability, in relation to gender and adolescence (Baird et al., 2021; Larson et al., 2016). When the experience of disability becomes difficult to contain in frames based on single identities, intersectionality expands our understanding of the multifaceted experience of disability and its unique forms of dis/advantage (McCrae, 2019).

GBV matters to girls and women, families and societies, and our common future. It is an issue of public health (Namatovu et al., 2018), human rights (Meer and Combrinck, 2015), and development (UN, 2015), and is a threat to the reduction of inequalities (Starrs et al., 2018). I approach GBV primarily as a development issue, an impediment to the progress towards equality for persons with disabilities. The UN General Assembly (1993) defines GBV as 'any act of violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women'. Thus, GBV can be defined as sexual, physical or emotional violence aimed at women or girls (Muluneh et al., 2020). The following definitions of these forms of GBV resonate throughout this article: sexual violence as unwanted sexual comments, sexual acts and attempts of sexual acts (Valentine et al., 2019); financial violence as denying access to and control over basic resources (Stylianou et al., 2013); emotional violence as verbal abuse, threats of violence, and humiliation (Jewkes, 2010); and physical violence as physical aggression resulting in physical harm or death (Bukuluki et al., 2021).

The concept of violence within SRH services is developing rapidly (e.g. Chadwick, 2021; Lappeman and Swartz, 2021; Lévesque and Ferron-Parayre, 2021). Drawing from the literature on violence in the context of maternal care, a definition of violence that embeds the individual, structural and policy levels proves useful (Freedman et al., 2014; Lappeman and Swartz, 2021). Violence can be understood as structural and when woven into the fabric of society, as perpetuating social and health inequalities (Farmer, 2013; Sadler et al., 2016, p. 50). Structural violence manifests at organisational and collective levels yet is also felt deeply by individuals (Lappeman and Swartz, 2021). Individuals may also become perpetrators within systems of oppression even when they do not wish to harm others (Farmer, 2013; Lévesque and Ferron-Parayre, 2021). These interpersonal dynamics of violence can be approached through the feminist ethics of care paradigm (Kittay, 2011), the focus of which is not on the normative understanding of violence, which draws from, for instance the international human rights standards, but on the situational and contextual nature of the networks of care and violence (Held, 2010). This paradigm has inspired the exploration of the studied phenomenon through a relational lens.

The coloniality of knowledge production may also perpetuate epistemic violence towards Tanzanian adolescents with disabilities (Dotson, 2011; Ndlovu-Gatsheni, 2018; Ned, 2022). Disregarding the intersectional perspectives of violence in the context of accessing SRH services may risk this epistemic violence being translated into other forms of structural and systemic violence (Ned, 2022, p. 486). Next, I contextualise the structural violence in the Tanzanian context of accessing SRH services, after which I present the methodological approaches to addressing the epistemic injustice of the studied adolescents.

3. Contextualising disability, adolescence, access to sexual and reproductive health services, and gender-based violence in Tanzania

The challenges that Tanzanian adolescent females with disabilities face in terms of access to SRH services and GBV are set against a landscape of complex political, discursive and social norms (Bylund et al., 2020; Sambaiga et al., 2019). Tanzania was among the first signatories of the CRPD and the Optional Protocol in the East African region (Mitra, 2018). The nation is committed to multiple international legal and policy instruments that reaffirm its obligations to respect, protect and fulfil the SRHR of adolescent females with disabilities as well as to ensure their freedom from violence.[1] Nevertheless the intersection of adolescence and disability remains ambiguous in policies and legislation, which place disability under the 'vulnerable groups' category, ignore any unique forms of disability-specific violence and neglect disability-specific actions.

For instance, the National Health Policy Health Sector Strategic Plan (HSSP IV) and the Adolescent Health and Development Strategy of 2018–2022 set the standard that adolescents, irrespective of their disability, have a right to access SRH services that are appropriate and relevant for their needs. These standards, however, lack a definition of the terms 'relevant' or 'appropriate', and contain no specific guidance for adolescents with disabilities as service users. The above shortfalls are also present in the Tanzania National Plan of Action to End Violence against Women and Children (NPA-VAWC 2017/2018-2021/2022) (United Republic of Tanzania, 2016) which is currently being updated.

The social and gender norms related to disability often have a greater influence than policy and legislation on how persons with disabilities, and their SRH, are

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[1] UN Convention on the Elimination of Discrimination against Women (CEDAW) (1979), UN Convention on the Rights of the Child (CRC) (1989), Agenda 2030 for Sustainable Development (2015); International Conference on Population and Development (ICPD) Programme of Action (1994), Nairobi Statement ICPD+25 (2019), Maputo Protocol (2003), and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (2018).

perceived in their communities (Onazi, 2020; Peta, 2017). These norms often exclude Tanzanian adolescents with disabilities from community life, deny them access to education, and lead to various negative health outcomes (Aldersey, 2012; Quinones et al., 2021). Furthermore, extensive evidence indicates that the stigma towards adolescents in SRH services is prevalent in Tanzania and hinders the access of adolescents, including those with disabilities, to SRH services (Mbeba et al., 2012; Mesiäislehto et al., 2021; Nyblade et al., 2017). GBV against adolescents is socially normalised in Tanzania (Abeid et al., 2014; Mlyakado and Li, 2019). Furthermore, evidence that women and girls with disabilities are disproportionately affected by GBV is gradually accumulating (ADD International, 2016; Greenwood et al., 2016). Like other forms of GBV in Tanzania, violence in SRH care settings is widespread and systematic in nature, as it is rooted in patriarchal structures and gendered stereotypes of the role of women in society; and is often committed with impunity (Kujawski et al., 2015; Sando et al., 2016).

The above contextual and structural factors tend to marginalise adolescent females with disabilities in Tanzanian society. However, how these factors are manifested at the individual level remains largely unknown. This article examines the largely unexplored epistemic standpoints of Tanzanian adolescent females with disabilities to gain a more comprehensive understanding of this topic and to counteract the coloniality of knowledge production.

4. **Methods**

This study is grounded in the constructivist paradigm (Denzin and Lincoln, 2018) and aims to understand the social world of its participants. In my quest for rich exploratory data, I used qualitative participatory research methodology. A research triad consisting of the researcher, a Tanzanian research advisory committee and a Tanzanian research assistant with disabilities was established in collaboration with the Tanzania Federation of Disabled People's Organisations. This cross-disability triad ensured that persons with disabilities maintained an active stance throughout the research, which was crucial for developing appropriate methods, interpreting data, and validating the results (Grischow et al., 2021; Kuper et al., 2021; Wickenden and Kembhavi-Tam, 2014). Due to their roles, the expert members had knowledge of the status of females with disabilities beyond their own experiences, making them insightful sources of information (Katsui and Mojtahedi, 2015; Sanderson et al., 2013).

My position as a European female in her late thirties, a doctoral candidate in international development studies, and a mid-career international development professional has influenced the research to some extent. However, the participatory research design, residing in Tanzania for nine years and the experience in engaging with adolescents with disabilities in community development programmes proved useful in making sense of the studied phenomena. As I do not share the experience of disability with those whom I have collaborated with in this research I practiced self-reflexivity to recognize and avoid assumptions based on my own experiences. Although my mind was already ideologically wired into the human rights framework, my long-term presence and experiences in Tanzania allowed me to critically reflect on it.

A purposive sampling frame was established together with the research triad to identify and recruit the study participants. The data were collected in three regions across 13 locations. The participants were 136 Tanzanian females with disabilities, aged 10 to 19. Some of these adolescents were deaf (n = 42), and one deaf participant also had physical disabilities. Some participants had physical disabilities (n = 33). Of those with albinism (n = 32) some also had partial vision (n =11). Other participants had intellectual disabilities (n = 13), blindness (n = 12), and partial vision (n = 4).

The research employed the method of empathy-based stories (MEBS), which is based on constructivist epistemologies, and sees reality as contextually and socially constructed (Eskola, 1997). Empathy-based stories (EBS) are fictional short stories narrated by study participants as a response to a frame story (Posti-Ahokas, 2013). Although the primary focus of MEBS is not to investigate the experiences of the participants, but rather their perceptions; it enables participants to disclose their lived experiences if they so wish. MEBS is an ethically sensitive data collection method, as it allows participants to distance themselves from sensitive and stressful topics (Wallin et al., 2018).

The frame stories centred on two protagonists, Fatuma and Nuru, and two scenarios based on the common reasons that adolescent females seek SRH services in Tanzania: pregnancy and sexually transmitted infections (STI) (Mbeba et al., 2012). To capture the perspectives of the participants, I used the following frame stories:

Fatuma John is an 18-year-old girl with disabilities, and she is pregnant. She needs to attend the health clinic. After visiting the clinic, she feels happy and safe. Tell us what happened at the clinic that made her feel happy.

Nuru Hassan is a 15-year-old girl with disabilities. Nuru has a disease in her private parts, and she is experiencing discomfort. She needs to see the doctor. In the meeting with the health professional something goes terribly wrong. Afterwards Nuru is really upset. Tell us what happened when she met the health professional. Tell us what disturbed her so much.

The frame stories were developed by the research triad and piloted prior to data collection. The stories were compounded with audio and visual aids. The participants took part in the storytelling verbally, by writing in Kiswahili or by using Tanzanian sign language. The verbally collected stories were transcribed verbatim and then translated from Kiswahili into English. The quality of the translations was monitored by the research triad. The data comprised 257 EBS narrated by the 136 Tanzanian females with disabilities. The EBS were on average 902 characters long. In addition, two focus group discussions (FGD) (Breen, 2006) were held with the research advisory committee, during which preliminary results were discussed and final results were validated. This triangulation of the data from the EBS and the FDG strengthened the validity of the research and reduced researcher bias, as multiple streams of knowledge were utilised.

The design and methodology of the study were informed by various ethical considerations, such as ensuring the meaningful participation of persons with disabilities across different research phases and guaranteeing reasonable accommodation and accessibility (van der Heijden et al., 2019). To ensure informed consent, information sessions were held with the participants and their guardians on the research sites. An 'explain-back' protocol (Talevski et al., 2020) was used in the process of obtaining informed consent, followed by the written consent of the participants and their guardians. The National Research Ethics Committee at the National Institute of Medical Research in Tanzania granted ethical approval for this research[2].

The EBS were analysed as one entity beyond the division created by the story variations through an abductive data analysis approach (Timmermans and Tavory, 2022). This approach is exploratory and although guided by existing conceptual or theoretical frameworks, it does not attempt to fit findings into them; it leaves room for

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[2] Ethical clearance reference NIMR/HQ/R.8a/Vol. IX/2970

conceptual and theoretical contributions (Flick, 2017). This means that the current understanding of the forms of GBV, as described above, was used as a basis. Then, the epistemic standpoints of the adolescent females with disabilities were used to challenge these and gain a more comprehensive understanding (Kennedy and Thornberg, 2018). Thematic analysis (Vaismoradi et al., 2013) was employed to analyse the EBS. The appropriateness of the themes used for this paper was discussed with the research advisory committee until a consensus was reached on the following: forms of GBV when accessing SRH services, inaccessible and inappropriate communication, and collective dynamics of accessibility and protection.

5. Results

In this section, I present the results of the analysis as directed by the methodological choices related to the frame stories; adolescent pregnancy and STIs. First, the different forms of GBV embedded in the narratives are discussed, then structural violence through the issues related to inaccessibility and inappropriateness of services are addressed, and finally, I reveal the findings related to the collective dynamics of accessibility and protection.

Forms of gender-based violence when accessing sexual and reproductive health services

Emotional violence was the most common account of violence linked to SRH service access. The adolescents' narratives revealed that emotional violence could occur when seeking SRH services, at homes, *en route* to and at health facilities; by family and community members, friends, and health care providers. The participants' accounts entailed emotional violence based on social and gender norms. For instance, disability portrayed a person as a lesser human, and being an adolescent and unmarried was linked to not needing SRH services or being blamed for risky sexual behaviour.

He [the doctor] may have abused her with words, he might have told her to get out and that the [laboratory] results were bad news. He might have told her to get out because she is a person with disabilities, so that another person can come in. This is because persons with disabilities are not loved.

Participant with physical disabilities, aged 16

He [the doctor] may have said why did you go around so carelessly, and catch a sexually transmitted disease? Who do you think can treat you now?

Participant with albinism, aged 19

At times, the described emotional violence took the form of verbal abuse, neglect, and being ignored. This, compounded by the experience of physical pain, led to descriptions of despair.

She feels bad because when she goes to pee, it hurts. Now the doctor laughed at her and used offensive words. Nuru was very irritated because of the pain and because the doctor laughed at her.

Participant with physical disabilities, aged 16

I came home from the hospital as the doctor didn't listen to me. I had just been sitting there, very sick, my private parts were itching and in pain, but the doctor didn't listen to me, instead he ignored me.

Participant with blindness, aged 17

Emotional violence also took the form of refusal to provide services, withholding and delaying laboratory test results, or distorting the information related to the results.

Emotional violence was intertwined with the fear of poor health outcomes or even complications leading to death.

When I get in and explain to the doctor that I'm sick, that I'm feeling this way and that way, and he listens to me, but then he leaves me and goes out to attend to another person. But I was the first one here even before that person! Or after that he may tell me to wait as he is going to get his equipment. He leaves and when he gets back a lot of time has passed, and that's why a lot of patients lose their lives because the doctors don't really consider us patients.

Participant with blindness, aged 17

Economic violence was also apparent in the narratives as the refusal of others to contribute financially to the transport or service costs depicted controlling resources needed to access SRH services. Economic violence also took the form of misinformation about the costs of the services, which caused stress due to uncertainty about whether the patient could afford the service. In several narratives, the studied adolescents described access being compromised due to cost-related issues.

I may go to the hospital, and I'm told the treatment is five thousand shillings and when I go again, I'll be told it's fifteen thousand shillings. Now that will be bad.

A participant with blindness, aged 12

The participants' narratives also included perceptions of sexual violence in SRH services. Male SRH service providers in particular were described as having sexual intentions and suggestions. Their sexual temptations and propositions were carefully described by the studied adolescents in the context of interaction with the service provider.

Instead of listening and treating her, the doctor was thinking of something else, or the doctor got tempted to have her. This lady only required treatment but the doctor needed something else.

Participant with physical disabilities, aged 15

There are some doctors who are just crazy. You go to the hospital expecting to be treated but he starts doing other things instead of treating you. He starts telling you strange things. You get out of there angry and frustrated because you went there to seek medical treatment and not to be asked strange, silly questions or to be seduced.

Deaf participant, aged 14

The narratives also depicted interlinkages between financial dependence, economic violence and sexual exploitation. Some narratives indicated that the desire for privacy had led to the patient seeking services alone, without assistance, which in turn had resulted in exposure to sexual exploitation.

Overall, the studied adolescents' narratives shed light on why violence in SRH services often goes unnoticed, as power over them may be used to justify various forms of abuse and mistreatment. Evidence from other African settings aligns with my findings that this is a major concern in SRH services for persons with disabilities (McKenzie, 2016; Peta, 2017; Wudneh et al., 2022).

Inaccessibility and inappropriateness of the services

The narratives described inaccessibility of communication, information, transportation, and facilities hindering access to SRH services. Inaccessibility was perceived to complicate seeking, attaining, and engaging in one's SRH care. Health providers were portrayed in the narratives as unwilling to engage in alternative forms of communication; for instance, they would decline to use writing as a form of providing information or refused to speak directly to the deaf adolescent. This inaccessibility at times included accounts of violence; for instance, when measures that could have increased accessibility were intentionally withheld. Such actions may have long-term health implications and decrease individuals' use of services.

Accounts of violence were frequently compounded by inaccessible communication with the service provider and their lack of age-appropriate communication skills. When communication with the health care providers was insufficient, it could lead to having to just endure the health condition as demonstrated in what follows:

My genitals are itching and hurting, and I haven't been given any medicine. As I've not been given medicine, my genitals will continue to burn and if I try to go to sleep, I can't […]. So, I continue to suffer. The condition is so bad because the doctor and I failed to understand one another. But if we could understand each other well, I'd be given medicine and it would heal.

Deaf participant, aged 17

Victim blaming is a concurrent theme across a range of SRH-related experiences of female adolescents (Coast et al., 2019). It was also present in the narratives of the studied adolescents, compounded by the pervasive stigma towards adolescents as SRH users (Nyblade et al., 2017), making the service they received inappropriate, as exemplified here:

What disappointed her after the check-up and being told that she's sick, after hearing the results is when she felt bad and when she met a discriminating doctor who told her that you went around and look you caught sexually transmitted diseases, that's the reason why Nuru was not at peace and got angry.

Participant with albinism, aged 19

Victim blaming compounded by the experiences of disability, was also present in the narratives of the studied adolescents. For instance, Nuru, the protagonist, was blamed in the narratives for not being able to express herself well enough, for not behaving politely enough, or not understanding the information provided by the SRH service providers.

You can go to the hospital and get tested and then perhaps you're told that you have a certain kind of disease, of which you were not even aware. You leave the place feeling sad because you went there pregnant, and because you are a person with disabilities you were told that probably you have this and this condition. [...] But because you can't express yourself, which is why you got the problem in the first place, and that happens mostly to people who fail to express themselves.

Participant with physical disabilities, aged 14

Such examples depict also internalised victim blaming, as a result of the services that due to inaccessibility and inappropriateness due not respond well to the characteristics of the studied adolescents. Such shortcomings of these services may result in further marginalisation of adolescent females with disabilities.

Collective dynamics of accessibility and protection

The findings support the existing literature, which claims that despite many shortcomings, family and community remain the most reliable care and support system for marginalised children and persons with disabilities in many African and Tanzanian communities (Aldersey, 2012; Nyamnjoh et al., 2021; Onazi, 2020). Against this backdrop, the notion of accessibility in Article 9 of the CRPD, which conceptualises accessibility as an important aspect of *independent* living, appears peculiar, as in the narratives, accessibility was strongly linked to interdependence and relationality. It is also known that child protection approaches that emphasise individuals have not worked well in African settings because collective problem-solving is more socially accepted than individualised activities (Chilwalo, 2020; Mabeyo and Kiwelu, 2019). In line with previous research (Ringson and Chereni, 2020), the studied adolescents also described the pivotal role that informal support networks play in protection from GBV in SRH services.

These findings presented unique relational modalities for accessibility and protection in situations where GBV intersects with access to SRH services in the Tanzanian context. Rather than depicting formalised or institutionalised measures of accessibility, such as the provision of sign language interpretation, ramps, assistive technology, or facility-based assistive personnel, the narratives demonstrated reliance on their informal support networks. A deaf participant, aged 19, describes the informal relational aspects of accessibility in SRH services:

> *There should be somebody there to interpret or write down this information. Because Fatuma is deaf and maybe she doesn't want to take the medication, but if she had somebody with her that understands that about her, and if she was given the right medication and was helped by that person, if she had somebody who knew sign language or somebody like a parent or a husband [...] then they would assist her.*

Although the studied adolescents' narratives depicted how inaccessibility involves others in the access to their care, making it a collective effort, they also highlighted that inaccessibility could disrupt the relationship with the service provider and lead to negative interpersonal experiences and disharmony. The narratives included accounts of solidarity and support of adolescent females with disabilities that were situated in their communities, but in health care facilities, solidarity was scarce and not encouraged. This depicts a disconnect between the collective care available in families and communities, and the assumptions of individualistic care at health facilities.

6. Discussion

In this section, I discuss how the standpoints of Tanzanian adolescent females with disabilities challenge the current conceptualisations of GBV and suggest ways of rethinking violence through the lens of intersectionality and collective dynamics. This discussion is central, as it entails recognising the specific forms of GBV against the studied adolescents for the purpose of eradicating all forms of it.

Rethinking gender-based violence in access to sexual and reproductive health services through the lens of intersectionality

SRH services are a distinct element of response to GBV, but violence within these services often goes unnoticed and is neglected in GBV protection and response policies and standards, as is the case in the Tanzania NPA-VAWC. Furthermore, the specific gendered features of SRH care and its invisibility and intimacy, and the implications of such violence for further utilisation of SRH care services highlight the importance of further scrutiny of violence in such settings (Lévesque and Ferron-Parayre, 2021).

SRH care has been conceptualized as a sexist system as the gendered services are impacted by gender inequalities as supported by my findings (Lévesque and Ferron-Parayre, 2021). This study found that, in addition to sexism as a system of oppression, systemic ableism (Goodley, 2014), in the form of inaccessibility, was also a key barrier to SRH services for adolescent females with disabilities (Casebolt, 2020; Kabia et al., 2018). The views of the studied adolescents reflected services predominantly designed on the basis of singular perceptions of service users. The ableist assumptions embedded in SRH care resulted in inaccessibility, which inflicted 'physical and/or mental harm or suffering' (UN, 1993, definition of GBV) in the narratives of the studied adolescents. Thus, I argue that in Tanzania, societal norms related to disability, adolescence and gender, the health system, and policies, have established inaccessibility as a form of structural violence within SRH services for adolescent females with disabilities. These various normalised modes of information and communication, and the inaccessible infrastructure in the particular context of SRH care calls for reconceptualising the inaccessibility of SRH services as a form of violence. By rejecting the normalisation of inaccessibility, the perspectives of adolescent females with disabilities and their GBV knowledge in the context of SRH services can be revalued.

In addition to sexism and ableism, the present study raises the possibility that when Tanzanian adolescent females with disabilities try to access SRH services, structural violence based on ageism may also marginalise them. In the current study, access was influenced by a lack of age-appropriate, adolescent-friendly communication in the SRH services, the roots of which lay in the Tanzanian taboo of adolescent sexuality (Bylund et al., 2020; Nyblade et al., 2017) and human worth being based on seniority (Nyamnjoh et al., 2021). As these intersecting systems of oppression may produce negative SRH outcomes, life-threatening situations and further marginalisation, recognising sexism, ableism and ageism will help unveil violence in the context of accessing SRH services, especially that against adolescent females with disabilities.

Based on the intersectional perspectives brought forth in this study, I concur with Lévesque and Ferron-Parayre (2021) that acknowledging the particular, intimate context of SRH services, centring the voices of those affected by violence within these contexts, and identifying the systems of oppression inherent to the specific nature of SRH services is central for rethinking violence in access to SRH services. Violence, when extended to the particular, intimate contexts of SRH care, requires increasingly specific conceptualisations such as reproductive violence (Altunjan, 2021; Chiweshe et al., 2021; Laverty and de Vos, 2022), obstetric violence (Chadwick, 2016) and gynaecological violence (Rozée and Schantz, 2021). Thus, I concur with Lappeman and

Swartz (2021), on accurate terminology having implications for how research results are reflected in policy and practice.

The current study therefore suggests that the conceptualisations of violence in the context of accessing SRH services need to be more specific. They should not all be merely placed under the broader category of GBV (Chadwick, 2021), instead they should be approached through intersectional perspectives (Chadwick and Jace Mavuso, 2021). These perspectives could be further used to identify and address the specific mistreatment that occurs both in SRH services, and when accessing them. Furthermore, applying these more detailed conceptualisations in this critical area of research is of paramount importance for unveiling and addressing discrimination, non-consensual care and abuse that underpin the experiences of adolescent females with disabilities worldwide, without taking the diverse contexts for granted.

'Asymmetrical obligations': Towards accessibility and protection in the context of accessing SRH services

The Tanzanian context highlights other limitations of these conceptualisations. When designing services that respond to the characteristics of adolescent females with disabilities, the findings suggest considering conceptualisations that account for the interface of GBV and access to SRH services, without taking for granted the collective dynamics between individuals and communities (Levesque et al., 2013; Onazi, 2020).

Novel disability theorisations are increasingly emerging from the African continent, which, in the light of the findings of this study, have the potential to frame these collective dynamics in research on access to and protection in SRH services. Recently, Berghs (2017) and Bannink Mbazzi et al. (2020) have introduced African models of disability based on *ubuntu*, an African ethic of humanness and interdependence. Moreover, Onazi (2020) has drawn from African communitarian philosophy to theorise a path for African disability justice, which is based on community and relationships. Central to all these theorisations is the conceptualisation of personhood, for instance, the basis on which a person with disabilities is considered a full member of society and can enjoy services and protection on an equal basis with others (Imafidon, 2021; Nyamnjoh et al., 2021).

The collective dynamics presented in the study findings reflect the African ethic of interdependence, through which individuals are viewed in relational rather than individualistic terms (Berghs, 2017; Ogude, 2019; Onazi, 2020). The narratives of the studied adolescents depicted how navigating access to SRH services resembled what Onazi (2020) described as 'asymmetrical obligations'. According to Onazi (2020), asymmetrical obligations are not based on mutual reciprocity; they are obligations for those who, in a certain time and place, are in a position to support and assist others. The study findings however also emphasise that although collective dynamics may enable access to SRH services of the studied adolescents they at times also constrain it.

The findings of this study also support Katsui's (2012) view that the human rights-based approach to disability offers very little or no immediate relief for persons with disabilities who require day-to-day assistance to overcome barriers in environments where no formalised support systems are available (see Heikkilä et al., 2020). The human rights-based approach also has shortcomings when formal and institutionalised accessibility does not exist and in contexts in which accessible structures may fail either momentarily or for longer (Katsui and Chalklen, 2020). As the findings of the study portrayed, overcoming barriers to safely accessing SRH services takes more than an individual claiming their rights, and the concept of asymmetrical obligations may be beneficial for re-imagining an accessible and protected access to SRH services that is responsive to the characteristics of adolescent females with disabilities in contexts such as Tanzania, which tend to value interdependence over independence. Collective dynamics should therefore be understood as an under-theorised resource for addressing violence against adolescent females with disabilities and access to SRH services.

7. Conclusions

This study has various limitations. The study explored access to maternal and STI services as directed by the frame stories, thus a broad spectrum of other SRH services were excluded. Moreover, the limitation of the EBS was that they were mainly based on perspectives and not experiences. This, however, was also a strength of the method, as it enabled the studied adolescents to talk about a culturally contested topic related to one of the most intimate spheres of human existence. If personal experiences had been investigated, this may have impeded participation in the research and excluded the valuable perspectives of the studied adolescents.

To conclude, this study is the first known study in Tanzania to explore how GBV intertwines with access to SRH services and to focus on the intersectionality of disability and female adolescence. It contributes to rethinking the conceptual apparatus of GBV through intersectional and contextual lenses. It highlights the potential of intersectional frames to identify, resist and address the normalisation of the ableist, sexist and ageist systems of oppression that impede access to SRH services, result in violence and contribute to further marginalisation. Rethinking GBV through intersectionality could potentially lead to the following: first, by rejecting the normalisation of the inaccessibility of SRH services and by reframing it as structural violence, a more disability-inclusive intersectional policy and programmatic interventions on adolescents' access to SRH services could be designed and implemented. Second, precision in how reproductive, gynaecological and obstetric violence are linked to realizing access to SRH services should be considered in policy and legislation at the national level, by departing from general definitions of GBV. Third, conceptualisations of SRH care and protection against GBV in relation to disability that draw from collective dynamics should be further explored to enrich human rights-based paradigms in contexts like Tanzania.

Conflict of interest

The author has no conflict of interest to declare.

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III

MENSTRUAL PAIN REALITIES OF YOUNG FEMALES WITH DISABILITIES IN TANZANIA: TOWARDS A NUANCED UNDERSTANDING OF PAIN AND EMBODIMENT

by

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Menstrual pain realities of young females with disabilities in Tanzania: Towards a nuanced understanding of pain and embodiment

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ABSTRACT

This chapter investigates embodiment through the social relational model of disability by centralising pain. The analysis focuses on the impairment effects and disablism of menstrual pain and counteracts the coloniality of knowledge through the epistemological standpoint of 63 young Tanzanian females with disabilities. The results show that menstrual pain impacts both their public and private lives by adding a layer of oppression to disability experience. The findings demonstrate that pain denial is a pathway for young females to navigate amidst the potentiality of full social personhood. The chapter makes novel suggestions to global and public health professionals, academia and the state regarding approaches for validating the menstrual pain of persons with disabilities.

1. INTRODUCTION

Menstrual pain affects three quarters of females under the age of 25 (Armour et al., 2019). Menstrual pain can greatly interfere with participation in daily activities and promote emotional distress (Wong, 2011; Pembe & Ndolele, 2011; Emmanuel et al., 2013). However, it has been socially invisibilised through pervasive negative messages regarding menstruation (Przybylo & Fahs, 2018; Ssewanyana & Bitanihirwe, 2019). As this negativity leads to a lack of opportunities to express subjective experiences, menstrual pain is often invalidated, despite its severity and frequency in populations (Patsavas, 2014; Jones, 2016). Although globally there is an increasing interest in understanding multifaceted menstrual experiences (Crichton et al., 2013; Hennegan & Sol, 2020; Hennegan et al., 2019), studies have primarily focused on mapping the accounts of menstruation of the general population, disregarding the intersection of disability and the global South. Large gaps exist in our knowledge regarding the accounts of menstrual pain of persons with disabilities (Wilbur et al., 2019; Sommer, 2016) as they have often been systematically excluded from formal processes of knowledge production (Scully, 2018) and as there is a tendency to neglect their pain experiences (Patsavas, 2014).

By centralising pain, we explore gendered impairment effects and disablement in the context of the United Republic of Tanzania (hereafter Tanzania). Tanzania has undergone an attitude shift in favour of persons with disabilities, which is visible in its disability policies (United Republic of Tanzania, 2004; 2010; Mitra, 2018). Despite Tanzania being an East African forerunner in disability rights, this has not translated into significant gains for persons with disabilities (Aldersey, 2012; Aldersey & Turnbull, 2011), perhaps due to the inability of the policies to inspire social change (Onazi, 2020). The neo-colonial connotations related to the development and human rights apparatus may also potentially interrupt the existing social and cultural norms (Fay, 2019). Due to the paucity of disability scholarship and comprehensive national disability data from Tanzania, critical perspectives on gender, age and disability are scarce (Amuri et al., 2011; Morley & Croft, 2011; Dewhurst et al., 2012; Evans & Atim, 2011; Lehtomäki, Tuomi, & Matonya, 2014; Njelesani, Couto, & Cameron, 2011).

The tendency to neglect the issue of pain is also visible in the theorisations of disability scholars (Kafer, 2013; Rohleder et al., 2019; Thomas, 2012). In addition, since it has been estimated that 80% of persons with disabilities live in the global South (World Health Organization, 2011), there is a call in disability studies to address the domination of the global North in conceptualisation of disability (Grech, 2015; Meekosha & Shuttleworth, 2017). In order to begin to remedy the above gaps in the literature, we responded by counteracting the coloniality of knowledge on pain through the epistemological standpoint of young Tanzanian females with disabilities. Against this background, we asked how impairment effects and disablism were perceived within the context of menstrual pain and how, in relation to menstrual pain, they affected the psycho-emotional well-being of the 63 study participants.

This chapter is divided into five parts. First, as preparation for the empirical material we present how disability has been theorised over time, what are disability scholars' stances on pain and the shortcomings of conceptualising embodiment. We then turn to demonstrate the practice of knowledge production for this study in the Tanzanian context. Then follows a description of the structural disablism faced by young females with disabilities, and against this backdrop we present our findings on the menstrual pain accounts within the social relational model of disability. Finally, we discuss the coloniality of pain denial and end this chapter by summarising our findings and proposing actions for global and public health professionals, academia and the state.

2. EMBODIMENT AND PAIN IN DISABILITY STUDIES

Menstrual pain provides an intriguing perspective to embodiment in disability studies. We will discuss this by exploring the complex relationship of embodiment and pain using theoretical approaches to disability – its gendered nature; and its embeddedness into social meanings. By 'pain', we refer to both the physiological process of pain and the pain experienced primarily as emotional pain (Jones, 2016). We refrain from making clear distinctions and embrace Price's concept of *bodymind*, which emphasises the integration of the physiological and emotional aspects of pain (2015:269-270).

The medical model of disability has long dominated the understanding of disability (Goodley, 2011). The response of this model to disability was to configure the disabled body through correction, thus locating disability exclusively in individual bodies (Siebers, 2006:173). This model recognises pain as a private and subjective experience and ignores the social contexts of people with pain, and by doing so, neglects how pain is experienced and culturally embodied in people's everyday lives (Smith, 2019). Disability studies are a response to the normative expectations of the medical model that seeks to move beyond the impairments of an individual body. It conceptualises disability as a phenomenon of the interrelationship between persons with disabilities and their environment. The social model of disability emerged in the mid-1970s as an alternative, politicised view of disability (Oliver, 1986; 1990). It shifted attention from the medical agenda to politics and citizenship (Paterson & Hughes, 1999). In other words, the social model of disability reframed disability as an issue of injustice in societies that are designed for those without disabilities (Rohleder et al., 2019). This theorisation shifted the focus from the impairment itself to the disabling effects of society.

The social model of disability framed impairment as separate from disability (Oliver, 1990). This allowed many scholars to turn their attention away from the personal tragedy of impairment to the public domains of disablism (Goodley, 2011). As disability and impairment are not compartmentalised but meet within one body, this distinction challenged the link between body and disability and also criticised and banalised the social model. When feminist disability scholars, for instance, would articulate their personal experiences of impairment, pain and tiredness being disabling in their own right (Morris, 1992; French, 1993; Crow, 1996) the social model-oriented disability scholars began to fear that such emotional and experiential dimensions of disability would enhance stereotypes of vulnerability (Finkelstein, 1996). Due to such concerns, there has been resistance to conduct research in areas of embodied experiences (Rohleder et al., 2019), which in turn has caused failure to adequately address the fundamental issue of embodiment (Marks, 1999; Thomas, 1999).

Carol Thomas (2007; 1999) altered the social model of disability into a social relational model of disability, which contributed to the reintegration of embodiment into disability studies. It suggested that not all barriers experienced by persons with disabilities are merely social by origin but there are also disabling barriers that operate on a more personal level (Reeve, 2014a). According to her, "*disablism* is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being" (Thomas, 2007:73, o*ur emphasis*). The concept of *impairment effects*, on the other hand, refers to restrictions to activities imposed on people as a direct ramification of having an impairment (2007; 1999). These are different from the restrictions imposed on people with impairments as a result of disabling actions by others (Stalker, 2020).

This theoretical framework of structural and psycho-emotional disablism is useful for understanding the lived experience of disability. Whereas *structural disablism* refers to the inaccessibility of buildings or the denial of information, and directly affects what a person can do, *direct psycho-emotional disablism* materialises in the relationship that persons with disabilities have with others or themselves. Such agents of disablism can be strangers, health care professionals and family members. Disablism often includes invalidation and disavowal of the person with disabilities and can result in an *internalised oppression*

(Reeve, 2014b). The oppression on the inside 'is about being made to feel of lesser value, worthless, unattractive or disgusting' (Thomas, 2004:38). *Indirect psycho-emotional disablism* recognises the emotional impacts of structural disablism, such as the emotions triggered by the inaccessibility of services or information. Ferrie and Watson (2015) argued that disability studies to date have not sufficiently explored how impairment itself can have psycho-emotional impacts by disabling people in their inner lives. Ferrie and Watson (2015) therefore introduced the concept of *psycho-emotional impairment effects* as the missing piece in the social relational model of disability. In this chapter, these elements of the social relational model frame our analysis in conjunction with cultural narratives of menstrual pain.

Cultural narratives of menstruation, apparent also in Tanzania (Sommer 2013b), have inspired a cultural code of silence and shown that menstruation is constructed as negative, deviant and dirty to the extent that women feel that, in the natural state, their bodies are disordered and need to be managed (Phillips-Howard et al., 2018; Hennegan et al., 2019; Bobel, 2019; Przybylo & Fahs, 2018). Menstrual pain is invalidated because of 'able-bodied expectations of performance and temporality that do not account for the cyclicality of menstrual bleeding and pain' (Przybylo & Fahs, 2018). As the absence of menstrual pain constructs the ablebodied norm, girls and women are required to hide their bodily needs and sensations. As we proceed to transcend beyond the public and private effects of social oppression by centralising pain, we embrace these narratives of menstrual negativity, containment and denial of pain (Przybylo & Fahs, 2018) and locate them in the theoretical framework of the social relational model (Thomas, 1999).

3. METHODOLOGY

This study utilises data that were collected for a study exploring the menstrual perceptions of young Tanzanian females with disabilities in spring 2019. The method of empathy-based stories (MEBS) was employed to acquire information, experiences and ideas that were embedded in the narratives of the participants. Empathy-based stories are fictional short stories narrated by research participants as a response to a frame story (Eskola, 1997; Posti-Ahokas, 2013). By storytelling, the participants utilise their personal experiences and thoughts and also reflect the societal context in which they live (Karlsson, 2011). However, the method also allows participants to discuss the frame stories from an objective perspective if they wish, making it an ethically suitable data collection method when studying sensitive subjects such as menstruation (Wallin, Koro-Ljungberg & Eskola, 2019). Persons with disabilities are frequently dismissed as knowers as they are seen to lack the resources to sufficiently express the significant aspects of their experience (Mietola, Miettinen & Vehmas, 2017). Thus, their knowledge is not fully utilised and benefited by society (Scully, 2018). However, storytelling has proven to provide participants from various backgrounds and of different ages with a voice, allowing them to contribute to the discussion on the given topic (Posti-Ahokas, 2013; Sinkkonen et al., 2017) and regarding them as competent experts of their culture (Wallin, Koro-Ljungberg & Eskola, 2019).

The participants consisted of 63 Tanzanian females with disabilities, aged 12 to 24 years. The majority reported having a physical impairment (n=43) whereas the rest had intellectual disabilities (n=6), hearing impairments (n=3), partial visual impairments (n=3), albinism (n=2), dwarfism (n=1) and heart disease (n=1). One participant had both an intellectual impairment and a physical impairment and three participants did not mention their disability. Through purposive sampling, the participants were reached both in and out of school settings. All of them had received some training on menstrual health. Written consent for voluntary participation was obtained from the participants and their guardians. Informal focus group discussions were also conducted prior to the collection of the verbal stories to serve as icebreakers for a culturally sensitive topic. The cultural suitability of the stories was evaluated by a Research Advisory Committee (RAC) consisting of Tanzanian persons with disabilities. Ethical approval for this research was obtained from the National Institute of Medical Research in Tanzania.[1]

Two different frame stories were used during data collection, both consisting of a positive and negative variation of the story. The topics addressed by the frame stories were performance of daily activities during menstruation and self-perception caused by different perspectives on menstruation. The four-frame story variations are as follows:

> ***Frame story 1***
>
> *1.1 This story is about a teenage girl with a disability. The girl is menstruating, and she performs her daily activities as usual. Empathise with the girl and explain what makes her able to perform her daily activities, such as family life-related tasks, education and social activities, as usual while menstruating.*
>
> *1.2 This story is about a teenage girl with a disability. The girl is menstruating, and she is not able to perform her daily activities. Empathise with the girl and explain what makes her unable to perform her daily activities, such as family life-related tasks, education and social activities, while menstruating.*
>
> ***Frame story 2***
>
> *2.1 This story is about a teenage girl with a disability. The girl is told that menstruation is a completely natural and normal process in a woman's life. Empathise with the girl and explain how this perception of menstruation affects how she sees herself as a young woman.*
>
> *2.2 This story is about a teenage girl with a disability. The girl is told that menstruation is shameful, dirty and disgusting. Empathise with the girl and explain how this perception of menstruation affects how she sees herself as a young woman.*

Each participant responded on a randomly designated variation of both frame stories. This resulted in 27–35 stories for each story variation, a sufficient quantity for analysis purposes (Eskola, 1997). Hand-written stories were collected from 44 participants who were able to express themselves fluently in writing. Verbal storytelling was conducted with 19 participants with intellectual disabilities, more severe physical impairments and sensory impairments. The participants who wrote their story had an hour to complete their stories, whereas the duration of the verbal story recordings varied from 14 to 35 minutes, conforming to each participant. The data collection was conducted in Kiswahili,

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[1] NIMR/HQ/R./a/Vol.IX2970.

the *lingua franca*, in cooperation with a native Kiswahili-speaking research assistant. Disability accommodations were provided according to participants' characteristics.

In addition to the menstrual narratives, the data included interviews of six female leaders from organisations working with persons with spine and spinal cord injuries, psoriasis, intellectual disabilities, and deaf-blindness. Additionally, one expert represented the viewpoint of the menstrual health management of persons with disabilities. The expert interviews provided an overview of the status of persons with disabilities in Tanzania, specifically of those who menstruated. This formulated a contextual frame for the pain perceptions of menstruating young females with disabilities in the context of Tanzania. The expert interviews and the verbal narratives were transcribed and translated into English together with the written stories. All the data were also carefully anonymised to ensure confidentiality and privacy.

Thematic content analysis was applied to analyse the data. The menstrual narratives were analysed as an entity beyond the division created by the story variations. During the process, we realised that menstrual pain was distinctly one of the main factors deterring the daily activities of young women during menstruation. Pain was mentioned in 41% of the stories, being the most common denominator across menstrual perceptions and the most frequent way to describe menstrual realities. This sparked our interest in the links between disability embodiment and pain. Thus, for the purpose of this research, we coded the content of the stories, focusing on any narratives mentioning pain. The codes were categorised into themes following the social relational model of disability; disablism, psycho-emotional disablism, impairment effects, and psycho-emotional impairment effects.

We acknowledge that we were not able to achieve a comprehensive picture of the pain perceptions of the participants, as pain was merely discussed in the stories insofar as it was evoked and guided by the setting of the frame stories. When using empathy-based stories, it is also noteworthy that the narratives of the participants might reflect the participants' own perceptions and experiences or might be completely imaginary. Regardless, they are still often rooted in culturally shared meanings, mirroring a subjective view of reality (Eskola, 1997). Triangulating data from multiple sources, namely empathy-based stories, expert interviews and RAC proceedings, enhanced the in-depth interpretation of the data and increased the validity of the overall study. For example, the RAC provided contextual perspectives that explained the data generated by the MEBS. Such triangulation, which involves obtaining different but complementary data on the same issue, makes it possible for researchers to obtain a more comprehensive understanding of the research topic (Creswell & Plano Clark, 2018).

4. MENSTRUATION AND STRUCTURAL DISABLISM OF YOUNG FEMALES WITH DISABILITIES IN TANZANIA

This chapter provides an overview of the structural disablism in the realities of young females with disabilities in Tanzania, and illustrates the context for the pain perceptions of the participants of this study. Seven semi-structured interviews with female leaders of the disability movement in Tanzania were utilised to demonstrate here the interface of menstruation and disability. Due to their roles, the experts had knowledge of the status of females with disabilities beyond their own experiences which made them insightful sources of information.

The interviews revealed that despite some positive progress, the status of young females with disabilities remains largely neglected in Tanzania. The challenges they face depend eminently on the girls' disability, the socioeconomic position of their family and their rural or urban habitual residence. Due to stigma and poverty, children with disabilities are often excluded from community activities and kept at home. The experts stated that girls with disabilities were often sent to school too late and very few of them were able to continue their studies after elementary school (see also in Lehtomäki et al., 2014). Therefore, very few girls with disabilities in Tanzania proceed to obtaining a degree in higher education or reach positions that enable them to participate in decision-making. Furthermore, discrimination and lack of support for persons with disabilities was also prevalent at the community-level, especially in health care services and schools, as health care workers and teachers were often ignorant about their rights and needs.

Young females with disabilities often have various daily responsibilities within the home and family. Depending on their everyday functionalities and given opportunities, schoolwork, laundry, cooking and cleaning are their main daily duties, as for Tanzanian girls in general (Sommer, 2010). The experts' interviews strongly indicated that girls with disabilities often had very low self-esteem, which implies internalised oppression stemming from psycho-emotional disablism (Reeve, 2019; 2014b). From early on, their opinions tend to be overlooked, and decisions are made on their behalf. These decisions can concern anything from the position in which a girl with a spinal injury has to lay in bed to the man chosen for her to give her children. Furthermore, the discrimination and marginalisation that young females with disabilities face, tend to disempower them to act to improve their own circumstances.

According to the experts, and existing literature, menstruating young females with disabilities often carry a dual burden (also in Holness, 2013; Wilbur et al., 2019), which causes even further restrictions and disability in their lives. Many of the challenges indicated by the experts and the stories narrated by the participants corresponded to those of young females without disabilities (Wilbur et al., 2019; Hennegan et al., 2019). In addition, the experts highlighted two challenges that ultimately affected the menstrual pain management strategies of young females with disabilities in particular. First, lack of education and inclusive education material on menstruation and menstrual health was regarded as a major problem. Educating them, especially on menstrual matters, is not regarded as a priority among their families and communities. Menstruation is regarded as an unnecessary and even harmful subject to be taught to girls with disabilities as they are often considered asexual (also in Peta & Ned, 2019; Holness, 2013). Therefore, their knowledge of menstruation and menstrual health is often very poor which causes confusion and has a negative effect on their self-esteem.

> *People feel like they don't need this kind of education because they feel it's pointless to engage them with sexuality related issues [...] so they just feel like "No need to explain this to her because this information will not help her or she doesn't need it."*
>
> (Expert representative of persons with disabilities)

Second, the role of caregivers is crucial for many young females with disabilities in Tanzania, especially those with intellectual or physical disabilities. Caregivers often have insufficient knowledge on how to support the menstrual health of the persons they care for, which makes the girls who are dependent on their help particularly vulnerable. Due to the caregivers' ignorance, girls might be locked inside the house, left without menstrual products or restrained monthly during their menstruation. The experts also remark that the caretakers often lack the time and financial resources to stay with the girls during daytime, because they depend on the income generated from daily work outside the home. Building on the context demonstrated above, we then turn to present the findings.

5. MENSTRUAL OPPRESSION IN THE PUBLIC AND PRIVATE DOMAINS OF PAIN

In the pain accounts of the young female participants with disabilities, menstrual pain was described as having manifold effects and as distinctly interrupting everyday life. This chapter sets these findings against the theoretical framework of the social relational model of disability (Thomas, 2007; 1999). We discuss the model by integrating the conceptualisations of menstrual negativity, pain denial and containment of pain by Przybyla and Fahs (2018) into our analysis. Through this empirical analysis we demonstrate how pain, conceptualised as both a disability and an impairment, weaves together the social and the individual, the body and the mind, into disability embodiment.

5.1. Structural disablism as neglect for menstrual pain

According to Thomas (1999; 2007), exclusion of those with an impairment through cultural values and the way in which society is organised is called disablism. Although the menstrual pain accounts of the young women with disabilities did not include numerous examples of direct disablism, this does not mean that it was completely absent. Some of the more distinct encounters of disablism were demonstrated through poor accessibility of pain medication and lack of education on pain management. Indeed, the allocation of public health resources in society may be an explicit sign of structural disablism. The evident shortcomings of the public health provisions indicated negativity towards menstrual matters as well as societal neglect and denial of pain for young females with disabilities.

The severity and frequency of the pain incidents in the stories demonstrated that pain realities were intense, yet pain management strategies remained insufficient, which is in line with previous studies (see Hennegan et al., 2019). It was assumed that pain relief was not accessible and affordable due to low economic status and lack of menstrual knowledge. Even at school, the environment was not very conducive to accommodating and alleviating menstrual pain. Participants annotated that when in pain, it is better to stay at home than to go to school, even if it means falling behind with lessons. Recurrent absence from school, particularly for those with initially weaker school performance, may result in dropping out from school altogether (see Sommer, 2010). The absence of services at school to accommodate those in menstrual pain thus denied the participants opportunities for education, even if only temporarily. The affordability and accessibility of pain medication to a large extent depended on whether the parents provided money for it and whether the school had budget allocations for it; in other words, whether pain alleviation was prioritised.

Furthermore, traditional medicine was often considered culturally more acceptable than Western medicine, as pharmaceutical pain relief was believed to cause addiction or infertility. It was to be used for pain in severe cases only. According to the RAC members, in Tanzania, traditional health knowledge is often applied for pain alleviation and for instance, lemongrass, ginger and papaya may be used to treat menstrual pain. Research shows that globally the most common and effective ways of self-care for menstrual pain are non-steroidal anti-inflammatories (NSAIDs) and the contraceptive pill (Armour et al., 2019). The RAC members stated that the contraceptive pill, even if primarily for the purpose of pain alleviation, was not culturally acceptable for young females in Tanzania, as it might encourage them to make early sexual debuts without the fear of pregnancy (Armour et al., 2019). Financial aspects, females' status in society, cultural norms, and the attitudes towards persons with disabilities demonstrated disablement as inaccessibility to information and unaffordability of pain medication.

The neglect of pain relief is in part seen to result from the prioritisation of the containment of the menstrual flow, which means that priority is given to the provision of menstrual products rather than to pain medication (Bobel, 2019). The menstrual realities of young females with disabilities echoed the containment narrative, especially pertaining to pain. Talking about her first period, a participant with physical disabilities replied: “I got stomach pain, I told my mother and she bought me sanitary pads.” Although the intention of the mother's response to pain was most likely not to propose managing pain with a sanitary pad, the storyteller's choice of sequence of events implies that the pain itself did not receive much attention and that the containment of the menstrual flow was prioritised. In addition, it provides an intriguing example of pain as a socially accepted avenue of communicating menstruation in Tanzania.

The disablement that young females with disabilities face in accessing information on menstrual pain and support for its alleviation are manifold. The participants' narratives were generally dominated by pervasive menstrual negativity. Menstrual blood was perceived as contaminating and menstruating girls and women were considered dirty and potentially infectious. The experts remarked (also in Holness, 2013) that menstruators with disabilities are regarded as especially unclean. Harmful and erroneous beliefs about persons with disabilities, such as that all persons with disabilities have HIV, also provoke negative images regarding their menstruating status, which may prohibit them from receiving the help they need to take care of their menstrual health, including pain alleviation. According to an expert representative of persons with intellectual disabilities: “They have the belief that a person with a disability does not carefully wash herself when she is in that condition, they believe that this is a dirty person.”Furthermore, education of persons with disabilities is neglected in general, but particularly when it concerns sexual and menstrual matters. As highlighted by the menstrual narratives, education on menstrual pain management was even more uncommon. This was also asserted by an RAC committee member with physical disabilities regarding pain management knowledge: "Even if they had the money to buy from the pharmacy, they would not know what to ask for." Even though pain relief was described as not accessible and affordable for many, the research participants referred to it in a number of stories. However, there was no distinction between whether they referred to traditional or pharmaceutical pain relief.

In addition to the lack of education and poor availability of pain medication, unsuitable menstrual products were included in the list of factors that added to the pain experience of females with disabilities. According to the experts, access to adequate, hygienic menstrual products was a particular concern among girls with disabilities and exposed them to the risk of sores and skin infections. For instance, girls and women with albinism and other skin conditions with increased skin-sensitivity required high-quality products that are non-abrasive and do not cause skin irritation. Furthermore, to protect their skin, they have to change the product frequently, which might be too expensive for most families. Girls with visual impairments, in turn, were also reported to be vulnerable to skin problems as they are not aware of the quality of the menstrual products they are purchasing which might have resulted in using outdated or poor-quality pads.

> *Most of them, they end up using whatever they can get and then they end up with sores to the extent they can't really manage to walk and be comfortable, and yet they can't even talk about it. So, I feel very concerned with their situation because at the end of the day, if somebody gets sores every month, it's going to be serious in the future and as menstruation is a taboo, it's not something that's easy for them to speak about.*
>
> (Expert representative of persons with disabilities)

Ableism arose as one form of pain denial in the menstrual realities of the narratives. It includes a notion that encourages people to appear normal and productive, as non-productive bodies are considered abnormal (Wendell, 1996). According to the participants, menstrual pain was regarded as pain that is meant to be endured and contained while maintaining productivity. According to cultural beliefs, menstrual pain prepares you for the pain of motherhood. "What will happen if you are not able to endure the pain now? How about childbirth?", commented one member of RAC with a physical disability. Demonstrating ability through concealment of pain was one way of fulfilling social expectations.

Structural poverty at home and in society also had an impact on the accessibility of basic menstrual needs, such as pain medication and menstrual education. According to the experts, socioeconomic challenges were especially prevalent among young women with disabilities. The economic implications of losing income further supported pain denial. The participants demonstrated ways in which to challenge disablement by claiming agency through denying pain. When livelihood was dependent on daily income, pain could not be allowed to jeopardise income and employment. A participant with a hearing impairment shared a personal experience that explains why pain has to be ignored:

> *For example, myself when I have a menstrual period and experience stomach pain, walking is a challenge. I feel like it's a great effort, and I get serious pain, but I stay strong. After taking medication I continue plaiting hair even if I am at the salon, because my work is in the salon. I put warm water on my stomach and stay strong because I need to earn income as I need money and the job, too, but I have stomach pain. Therefore, I get pain relief and continue with the job.*
>
> (Participant with a hearing impairment)

Against this backdrop of how structural disablism impacts what a person can or cannot do, we next turn to disablism that operates on a more personal level.

5.2. Psycho-emotional disablism as pain altering the inner world

Psycho-emotional disablism emerges as an inner dimension of disablism, in which the socially imposed effects of disablism affect the inner world of persons with disabilities. Our findings show that menstruation causes various negative emotions, which support the claims that it is culturally constructed as negative (Przybylo & Fahs, 2018). Young females with disabilities feel insecure and fearful during menstruation because of the social stigma attached to it and to the disabled body. Having difficulties staying on track when they were on their period, noticing that they were menstruating or being unable to manage their menstrual flow or pain during their period caused fear of their menstruation being exposed. What is more, people often seemed to find it pointless and strange that girls and women with disabilities also menstruate. Implying that they should not menstruate would make them feel as if they were not allowed to be female and strengthened the feeling of being different. This form of menstrual oppression affected what these people could do or be, as it became internalised. Direct psycho-emotional disablism includes invalidation and disavowal of the person with disabilities (Reeve, 2019). According to Reeve, these negative messages about self-worth "are reinforced by cultural myths and prejudices about the inherent and undesirable status of disability" (2014a:123). As negative messages of menstruation co-existed with those of disability, they had the potential to further degrade self-worth and esteem.

Various psycho-emotional dimensions of disablism were prevalent in the accounts of menstrual pain. They indicated that young women were willing to go the extra mile to hide their pain experiences because of the social expectations placed on them, not only by others, but also by themselves. Notably, the narratives strongly indicated that personal suffering was dismissed because of menstrual shame as the source of the pain was shameful. By hiding their pain, the young women aspired to fulfil social expectations, to appear normal and accomplish their denominated tasks, and hoped that no one notices that they are menstruating. Continuing life as usual, despite the pain, was demonstrated through showing strength in order to conceal the negative, unwanted situation at hand. The negativity, taboos and silence surrounding menstruation made it difficult for young women to talk about their menstruation-related problems and needs, even with their family members. Hence, many of the girls and women ceased to seek advice and relief for their menstrual pain, thus lacking also much needed psycho-social support.

In other cases, feared, potential reactions of other people to the shameful source of pain made young women change their everyday practices. The ways that pain restricted their lives were often not directly forced on them by others but inflicted indirectly by social oppression through internalised menstrual shame and potential embarrassment. This internalised shame was well portrayed in one account, in which pain was not perceived as depressing until the participant understood that the source of the pain was caused by menstruation. For instance, demonstrating strong emotions resulting from intensive pain can be so stigmatising that continuing daily life through mere concealment of pain is impossible. Thus, refraining from everyday activities and social contact and staying at home is the only way of hiding their condition from others, as the following quote demonstrated:

> *She can't perform daily duties or even go to school because she's worried that when she gets to school, she will be in pain and vomit in front of people. People will be surprised and think: "What is wrong with this person?" and feel that it's shameful that she's in serious pain and her face is full of wrinkles. She can't do anything, and her feelings will be exposed to people in the classroom or to those who are passing by.*
>
> (Participant with hearing impairment)

The findings also demonstrated that the non-validation of menstrual pain was linked to menstrual negativity. Negative messages about menstruation and inadequate information on menstrual health and pain management influenced the inner world of the participants by contributing towards their confusion about bodily functions. Furthermore, normative images supportive of the able and non-menstruating body caused the participants themselves to disregard the pain. The importance of carrying out activities despite pain was demonstrated by a research participant with physical disabilities: "I take some medication. After a while I continue with my duties. Someone who doesn't perform her duties is lazy."

The narratives presented resting due to menstrual pain as laziness. Even requesting medicine to alleviate the pain was regarded as being lazy, as menstrual pain was perceived as the kind of pain that is supposed to be tolerated. This requirement of toleration was based on the understanding that pain is not related to sickness and is temporary. Pain medication was primarily taken to be able to perform instead of to alleviate pain and discomfort. One participant with a physical impairment explained that people become lazy because pain makes their bodies tired. This implies that performing daily duties was normalised and anything deviating from it was considered laziness. Containment of pain through staying strong and not being lazy was often also strongly connected to feelings of being shy, less worthy or having low self-esteem.

Participants also described fear of sexual violence in conjunction with menstruation. As sexual maturity is culturally linked to menarche (Sommer, 2013a), both the experts and research participants disclosed that young women with disabilities often feared the malicious intentions of men to impregnate them once they show signs of fertility (see Holness, 2013). Containing menstruation and hiding menstrual pain from the opposite sex thus derived from concerns for personal safety and bodily integrity. Menstrual pain, if evident, could at worst lead to sexual assault. One participant with physical disabilities demonstrated the reality of personal safety concerns and their relation to the concealment of pain:

> **Participant:** *"If you are in that condition, your friends, either at school or anywhere else aren't supposed to know, you stay strong all the time and you keep cooperating well with them in different activities like studying, making stories with them. Even other people at home are not supposed to know that you're in that condition because bad people might be sent to attack you."*
>
> **Co-researcher:** *"Why should they attack you, what will they do?"*
>
> **Participant:** *"They come to do bad things to you. [...] for example, rape."*

The participants' stories portrayed the different meanings and significance they placed on menstrual pain. The relevance of pain was sought from physiological aetiology. It is worth noting that the significance was quite mixed, not only negative, as described above, but also positive or normative. The positive aspects of pain significance could be interpreted as the participants' counteraction of disablism or structural oppression in the public domain. However, as the formulation of these appeared to take place in the personal realm, we propose that the accounts highlighting the significance of pain also challenged psycho-emotional disablism.

Some participants described menstruation and menstrual pain as signs of the body maturing and functioning as it is supposed to. The participants demonstrated appreciation for menstrual pain as an anticipated and desired experience. The data revealed that pain, when seen as natural and periodic, was often perceived as necessary, appropriate and bearable. In addition, as both the narratives and the expert interviews remarked, at best, menstruation and menstrual pain could provide a sense of unity and pride as it is experienced by girls of all abilities and represents shared meanings of growing up from a girl to a woman.

"Experiencing pain is normal for a woman. Even our mothers went through it, so we will also go through it", commented a participant with an intellectual disability and a physical impairment. Or, as an expert representative of persons with deaf-blindness expressed:

"This [menstruation] happens to any woman, so you are the same as me and not disabled, the difference is that you don't hear and see but [otherwise] we are both the same."

Although the significance of pain provided the potential to regain self-worth, it was, however, problematic, as normalising menstrual pain might hinder the urge to seek pain management options and subsequently exclude, deny participation, increase health risks, and alter the psycho-emotional well-being of girls with disabilities. In sum, the results indicated that the participants' perceptions of menstrual pain entailed various accounts of psycho-emotional disablism. Evidently, internal oppression caused by disablism created distinct barriers to participation and significantly affected the lived realities of young females with disabilities on a monthly basis.

5.3. Impairment effects of disabling menstrual pain

Accounts of menstrual pain that were not socially imposed can be understood through impairment effects (Thomas, 1999). The subjective pain realities included diversity of pain experiences and diverse personal reactions to pain. The inability to perform at a ‘normal’ level or to stop all activities demonstrated the impairment effects of menstrual pain. The effects portrayed hiding from society and complicating the performance of everyday activities. Consequently, the stories depicted diversity and subjectivity in the physical experiences. Some described slight pain, while others depicted intensive, restrictive pain. Nevertheless, pain illustrations constituted a significant part of the participants’ stories. Furthermore, menstrual pain did not only vary between individuals. Although it was generally considered cyclical pain that accorded with monthly menstrual periods, pain also varied greatly within and between personal menstrual periods, as the participants’ stories portrayed.

The participants described menstrual pain in various bodily locations, most commonly in the abdominal area. Headaches, vomiting and back pain were also frequently mentioned symptoms related to menstruation. However, menstrual pain was also depicted in more atypical body parts, such as the limbs, which was linked to physical disabilities. Upon clarification, one of the participants verified that their limb pain was specifically related to menstruation.

> *Not all, but some of us, when abdominal pain starts, it goes down to the feet and it takes like a week or two and then it ends. But also, you may not have a period for some time, or two months, and when it comes, it is in the form of heavy bleeding with blood clots and you experience serious pain.*
>
> (Expert representative of persons with spinal cord injuries)

Several participants confirmed that menstrual pain could be so intense that it affected their ability to walk. Some participants described menstrual pain as disabling. These stories pointed out that without the pain, menstruation would have very little effect on their lives and daily activities. The following indicates that menstrual pain might sometimes be more disabling to the young female than her impairment as illustrated by a participant with physical impairment: “Nothing is beyond my ability, only if I have serious stomach pain, then I am not able.”

Some of the stories suggested that menstrual pain was associated with tiredness and loss of energy. Where the aetiology of menstruation was not so clear, having pain was repeatedly referred to as being sick (see also Mason et al., 2013). Identifying themselves as sick seemed to justify to the girls that a natural reaction to pain and the interrelated fatigue was rest. Several participants regarded rest as the correct strategy to relieve pain. However, resting and sleeping were also seen to result in failure to perform daily activities such as work and school. For some participants, avoiding activity because of pain could also further lead to poorer physical functioning and immobility.

We also noted that some of the participants’ accounts included ways of challenging the impairment effects. Other participants tried to deny their pain to maintain their social role and identity in the family through, for example, persistently persevering through house chores. The cultural narratives of containment were strongly linked to this perseverance and as such demonstrated the fluidity of the categories of the social relational model. Challenging impairment effects were demonstrated through the desire to maintain normalcy, through everyday duties, going to school and work, and staying physically and socially active. Some of these ways of challenging impairment effects were also portrayed as effective pain management strategies.

To summarise, the narratives depicted three different ways to react to impairment effects of menstrual pain: ignoring the pain and continuing with daily activities as usual, acknowledging the pain and receding from daily activities either to rest or in order to hide the pain from others, and acknowledging the pain and continuing with daily tasks while actively pursuing the relief of pain in different ways.

5.4. Psycho-emotional impairment effects as inferiority embedded into menstrual pain

Disablism can cause psycho-emotional impacts, as discussed above but Ferrie and Watson (2015) have argued that impairment itself can have similar effects in the private domains of persons with disabilities. Our findings are congruent as menstrual pain was perceived as disabling in the personal realm. Menstrual pain as an impairment caused fear and distress that could not be apprehended by psycho-emotional disablism. The participants attached a variety of strong, negative emotions to the menstrual pain experience. A participant with an intellectual disability described how having serious stomach pain could make you feel like you were “losing your mind as you can’t even walk”. Not being able to complete the activities or maintain the roles they were used to due to pain felt disempowering and depressing. Perceiving rest as the principle strategy for pain relief contributed to stress and low mood. Furthermore, the stories indicated that menstrual pain caused the participants to hate menstruation, and even hate themselves.

> *That [menstruation] kept hurting me and made me regret being born a girl. I complained to my mother, why did you give birth to me as a girl? Women are not supposed to live in this community because they are supposed to lock themselves inside each month and hate themselves or at least experience pain every month while menstruating.*
>
> (Participant with physical impairment)

As discussed before, the participants responded to disablism by thinking they were inferior to other people when in menstrual pain. Feelings of inferiority towards oneself due to pain were understood here as psycho-emotional impairment effects. The participants’ accounts portrayed feeling inferior to themselves compared to a time when they had no pain, which perhaps echoed a yearning for their pre-menarche self or another time in their menstrual cycle when not on their period. The accounts of emotions, deeply embedded in the bodily sensation of pain, reinforce Ferrie and Watson’s (2015) integration of the psycho-social impairment effects into the social relational model.

To summarise, throughout this empirical analysis, we have portrayed menstrual pain as a disability and an impairment and highlighted the effects that this particular pain has on the lives of young females with disabilities in Tanzania. The intensity of pain, the availability of pain medication and knowledge of pain management, the personal significance given to menstruation, and the menstrual pain perceptions of the public may all have an impact on the way pain is managed. Overall negative perceptions of menstruation often appear to lead to negative responses to menstrual pain (Lee & Park 2015).

As there were overlaps and interaction between impairment effects, psycho-emotional disablism and disablism; the distinctions between the psycho-emotional dimensions of disablism and impairment effects in particular were not always clear. By demonstrating that the pain accounts could not be fully integrated into the social dimension as a disability, we portrayed how pain as an impairment can translate into internalised oppression in the psycho-emotional dimension. Furthermore, the results demonstrated that living with pain can be simultaneously normal and disabling. In the midst of the psycho-emotional disablism and psycho-emotional impairment effects, these negative emotions were challenged through explanations that normalised pain.

Menstrual pain, therefore, is the kind that weaves together both normality and abnormality, and illustrates the need to apply a more nuanced and less binarizing framework to embodiment. We have, however, explored embodiment and pain here through the available models, but dichotomies of the body and mind, and the self and others, are not features of African philosophies (Maybee, 2017). This invites us to examine disability, pain and embodiment beyond Western dualistic and individualistic boundaries. Next, we employ decolonial lenses to further contextualise our findings in Tanzania.

6. ALTERNATIVE UNDERSTANDING OF PAIN AND DISABILITY: NEGOTIATING FULL SOCIAL PERSONHOOD THROUGH PAIN DENIAL

Although many of our findings support disability theorising from the global North, placing decolonialising lenses on menstrual pain and disability embodiment expands and contextualises the analysis. Disability studies and movements from the global North focus heavily on independence and self-sufficiency of persons with disabilities (Goodley, Lawthom & Runswick-Cole, 2014). Such aspirations of independence and self-sufficiency were absent in the participants' accounts. Instead, various relational aspects emerged. This study is in line with other, albeit a limited number of studies in African settings, that emphasize the significance of enhancing of *networks of connection* as an avenue for disability justice (Dirth & Adams, 2019). The networks of connection emphasize identity and meaning as a part of belonging rather than improvement of individualistic ways of being (Aldersey, Turnbull & Turnbull, 2014; Dirth & Adams, 2019).

African communitarian philosophy, informed by the *ubuntu* philosophy, continues to shape contemporary Tanzania (Ellison, 2014). In African communitarian philosophy the group determines the focus of the activities of the individuals in society (Gyekye, 1987). *Ubuntu* is an African ethic of interdependence which portrays personhood in relational rather than individualistic terms (Berghs, 2017; Ogude & Dyer, 2019; Onazi, 2020; Keikelame & Swartz, 2019). *Ubuntu* provides a loose analytical frame in African communitarianism for how being a person or a human is distinguished. "Being born a human being does not grant one personhood" (Manzini 2018:20), but the community may grant or deny the status of personhood through a set of culturally defined behaviour rules (Ogude & Dyer, 2019). It has been argued that some identities, such as age, gender and disability, potentially close off the possibility of personhood (Ngubane-Mokiwa, 2018; Manzini, 2018; Goodley & Swartz 2016; Onazi, 2020). Based on Tagwa's (2000) conception of personhood from the African communitarian viewpoint, Onazi (2020) suggests in his theorisations on African disability justice that personhood is being opened to those who have not conventionally been acknowledged as persons. By embracing this opening of personhood for young females with disabilities, we demonstrate the struggle for personhood through pain denial.

Embodiment and pain are responded to by behaviours that are cultivated and learned within the cultures in which people socialise (Encandela, 1993; Maybee, 2017), thus we attempt to unfold some layers of coloniality for a deeper understanding of disability embodiment and menstrual pain. There are five concepts within Tanzanian pre- and post-colonial girlhood that are intertwined with the perspectives of our research participants. Firstly, the hardening process in which endurance of pain is central, is considered a part of maturing (Ndee, 2010). A similar 'hardening' mindset emerged in our findings as the social environment encouraged denial or endurance of menstrual pain in order to prepare for the pain of childbirth. Secondly, similar social expectations tied to motherhood were in accordance with the popular girls' game of *mdako*, a game that represents managing family life and daily duties, thus preparing girls for womanhood (Ndee, 2010). Thirdly, the game called 'lazy one' provided an unconcealed signal that society did not approve of youths' laziness (Ndee, 2010). We also identified socially imposed and internalised disapproval of laziness as a driver for pain denial in our participants' accounts. Fourthly, the concept of *adabu*, meaning good manners and consisting of a display of courtesy, obedience, respect as well as appreciating the value of hard work, (Fay, 2016; Ndee, 2010; Caplan, 1976), plays a remarkable role in the lives of Tanzanian children and youth in reaching and possessing the fifth concept, *utu* or full social personhood, which is regarded as necessary to be recognised as a full member of society (Fay, 2018; 2016; Chuwa, 2014).

These five notions of girlhood i.e. hardening, managing womanhood, disapproval of laziness, good manners (*adabu*) and full social personhood (*utu*) expand our understanding of the struggle of personhood. The accounts of the young females with disabilities in this study demonstrated negotiation of personhood through a display of the five notions of girlhood. Next, we examine *utu* further, as it provides an intriguing perspective on why young females with disabilities deny their menstrual pain. This draws us complex interaction between potentiality and actuality regarding the personhood of persons with disabilities and African disability justice (Onazi, 2020).

As demonstrated in this chapter, females with disabilities experience structural disablism related to menstrual pain and due to this, fulfilling social expectations and reaching *utu* may be disproportionately harder for them. The effects of pain on diligence can increase obstacles to personhood socially, physically and psycho-emotionally. As they are shadowed by the potentiality of personhood, fulfilling the social expectations of the five notions of girlhood becomes central for girls with disabilities as they seek full membership of society, possibly more than for other young females. In addition, being able to contribute is acknowledged as a source of pride for persons with disabilities in African settings (Katsui

& Mojtahedi, 2015; Aldersey et al., 2014). Although sometimes the networks of connection regarding, for example, household duties, may exploit persons with disabilities, they are nevertheless perceived to provide identity and meaning (Katsui & Mojtahedi, 2015).

We agree with Bullington (2009:100), that pain accounts do not only portray suffering from "the physical aspects of pain and discomfort but also from a loss of identity where one feels alienated and detached from things that used to give meaning to one's life". We identified an urgency to maintain normalcy despite menstrual pain, to enable productive contributions to one's family and community as these were pathways to claiming agency, meaning and identity. We thus propose that for the participants, pain denial was not a mere manifestation of self-sufficiency, productivity, independence, but a quest for *utu*, full social personhood. The access granted by *utu* to networks of connection, and vice versa, defines how young females with disabilities are isolated by pain and how they negotiate agency within their everyday lives.

Informal care and relationships are instrumental in the lives of many persons with disabilities in the global South, "enabling access to resources and often survival in the absence of formal safety nets" (Grech, 2009:780). Enhancing networks of connection thus can sustainably contribute to the access of pain management and alleviation for persons with disabilities in settings in which public health and formal care are not available or accessible. In financially scarce settings, networks of connection can replace what publicly funded individualistic, institutionalised systems of social security and protection offer in the global North (Dirth & Adams, 2019).

Young Tanzanian females with disabilities should not be denied access to networks of connection that can provide a meaning and identity and ways to negotiate full personhood. We suggest that the misalignment between oneself and the outside world that menstrual pain creates (Winance, 2006) could be mended if the way in which a young female with disabilities feels about her body, especially in connection with others, could be transformed through access to full social personhood, networks of connection and contribution. Including disability in the conceptualisation of personhood is essential, otherwise this "symbolic violence" (Watermeyer, 2009:97) of denying personhood will lead to internalised oppression and unclaimed agency (Watermeyer & Mall, 2016). Full social personhood, open for persons with disabilities (Onazi, 2020), combined with fluidity between oneself and others, and body and mind (Maybee, 2017), provide a much-needed framework for conceptualising menstruation, disability embodiment and pain in Tanzania and beyond.

7. CONCLUSION

In this chapter we have focused on the accounts of young Tanzanian females with disabilities through the social relational model of disability (Thomas, 1999) and discussed the findings through a decolonising lens of pain denial and access to full social personhood. We noted that by placing pain in the middle, novel approaches to understanding disablism, impairment effects and psycho-emotional disablism emerged, allowing a deeper understanding of how pain impacts both the public and private oppressions in the lives of persons with disabilities. The main findings demonstrated that disability, gender and global location add a burden to their lives. We also noted that through pain denial, these young females with disabilities pursue the achievement of full social personhood and their contributory roles that enhance a sense of identity and meaning which is more valuable than superficial self-sufficiency and/or mere physical independence.

We would like to propose the following recommendations for global and public health professionals. First, because of the persistent and compounding stigma surrounding menstruation and sexuality of persons with disabilities, concrete strategies for reducing stigma need to be included in sexual and reproductive health programmes. Second, active pain management-seeking behaviour among persons with disabilities should be encouraged and access to pain management ensured through targeted interventions. Third, such interventions should entail ways to address the psycho-emotional well-being challenged by menstrual pain. For academia, many questions remain unanswered in terms of the structural, social and cultural factors that shape the menstrual pain experiences of young females with disabilities in Southern contexts. As menstrual pain is diverse across young females with disabilities, more research is needed to understand whether different types of disabilities intensify menstrual pain experiences, especially in the global South, where a lack of rehabilitation services and other assistive technologies may lead to chronic pain. There is a need to continue highlighting the global, gendered and disabled voices, and to generate an in-depth understanding of how disabling pain intersects with different age and disability groups, the rural–urban divide, and socio-economic factors.

Finally, we suggest that efforts should be made to validate menstrual pain in the Tanzanian society as this may facilitate pain management-seeking behaviour from existing social support systems. We encourage the state to commit to acknowledging all citizens as potential contributors, including young females with disabilities who may face embodied injustices. This will grant them enjoyment of full social personhood and provide them with increased opportunities to contribute to family and community life.

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ANNEX 1 PROMPTS FOR STORY SESSIONS

General issues to address in the beginning:

1. How old are you?
2. There are no right or wrong answers, we need to have a good
3. This is not schoolwork and it will not be assessed.
4. Feel free to stop the storytelling anytime you wish, this is completely voluntary.
5. What you say is confidential and will not be connected to you or to your school.
6. Are you willing to listen to a story with us?

Fatuma's story: Prompt questions

1. How did she end up in this situation?
2. What are the things that the doctor can do to make Fatuma feel good?
3. What kind of advice would you like to give to the doctor of Fatuma?
4. What advice do you give to Fatuma?
5. Is there any advice you would like to give to someone else?

Nuru's story: Prompt questions

1. How did she end up in this situation?
2. What are the things that the doctor can do to make Nuru feel sad?
3. What kind of advice would you like to give to the doctor of Nuru?
4. What advice would you give to Nuru?
5. Is there any advice you would like to give to someone else?
6. After Nuru is sad what should she do?

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ANNEX 2

Guardian/Parent permission for your adolescent to participate in a PhD research study

Study title: Sexual and reproductive health and rights at the intersection of vulnerabilities in Tanzania

My name is Virpi Mesiäislehto, I am an associate researcher at the University of Dar es Salaam and a PhD candidate at the University of Jyväskylä in Finland. I am working under the supervision of Dr. Richard Sambaiga from Department of Sociology in the University of Dar es Salaam. I invite your child, with your permission, to participate in this study. This study is made with a participatory approach. It means that to generate knowledge about a certain group of people, they must also be involved as much as possible. The study coheres to a principle: “Nothing about them without them”. It is understood that more accurate and specific knowledge can be generated if the people are involved in research that is about them.

Before you and your child decide whether she will be a part of this study it is important for you to understand why I am conducting this research and what it involves. Please read this paper carefully. (Your child will receive her own consent form). I encourage you to discuss the study with your child. If your child has questions about the research, feel free to ask me.

Purpose

The purpose of this research is to understand the challenges that adolescent girls with disabilities, that are standing at the intersection of age, gender and disability, face regarding the access to knowledge and services regarding their sexual and reproductive health and rights in Tanzania. This study is divided into three sub studies. The study in which your child would be involved seeks to find answer to this broad question: what gaps exist in service provision and fulfillment of sexual and reproductive health of the vulnerable groups at the intersection of gender, age and disability?

To obtain this knowledge through this study and to provide information generated by the adolescents with disabilities themselves will strengthen the understanding of the situation adolescent girls with disabilities face in Tanzania. The research will also provide a voice for this people group and help to formulate more inclusive policies for people with disabilities. The objective of this study is to empower adolescent girls with disabilities and make them understand that their voices need to be heard and they have much important information that can benefit social research.

Procedure

If you give your child a permission to participate, she will join 2 times in a 2 hour group session where she will be a part of group discussion and participatory group activities appropriate for her age and disability. The discussion will be about the challenges she has faced in access to information and services regarding sexual and reproductive health and rights. If you and your child agree for her to take part in the research she can stop at any time and refuse to answer questions or to take part in an activity.

Confidentiality

All the answers your child provides will be confidential. To minimize the risk of confidentiality, your child's name will not be linked to anything she says during the research. When I write and present the results of this study I will not use your child's name or any personal information. All information provided by your child will be collected to an on-line service that is locked by a password and only accessible by me. No identifying information will be linked with the answers collected from your child.

Risks/discomfort

There are no physical risks for your child to take part of this study, however, some of the questions may make your child feel uncomfortable. If your child feels uncomfortable at any point of the research, she will not have to answer or take part in the activity. Your child can stop participating at any time in the study. Violation of confidentiality is a risk of all research, it is my utmost priority to minimize such risk.

Benefits

There is no benefit personally to your child or you for your child taking part in this study. However, as a result of the research, the sexual and reproductive health and rights of adolescents with disabilities in Tanzania may be expected to improve and the voice of adolescent with disabilities will be loudly heard.

Compensation/Payment

There is no payment provided to your child, however your child will be provided with tea and a snack and a compensation of transport. If your child requires special assistance due to her disability, such as a sign language interpreter, the assistance will be paid for in order to ensure her full participation.

Rights

Participation in this study is completely voluntary. You have the right to decline your child's participation in this study or withdraw at any time from this study without any penalty or loss of benefit of which you are otherwise entitled. Your child has the same right to decline to participate or to withdraw from the study at any time.

Questions

You and your child can ask questions about this study at any time, now or later, through my number +255766645103 or e-mail virpi.mesiaislehto@jyu.fi.

If you have any questions or concerns about your child's treatment regarding this study do not hesitate to contact the department of Sociology in University of Dar es Salaam, Dr. Richard Sambaiga +255767643600 or e-mail richsambaiga@gmail.com.

If you decide that your child can participate in this study, please sign and date below. I will give you the copy of this form to keep for your future reference.

Child's name in capital letters

Parent's / Guardian's name in capital letters	Date
--	--------------------------------
Parent's Guardian's signature or thumb print	Date
--	---------------------------------
Witness' name in capital letters	Date
---	----------------------------------
Witness' signature or thumb print	Date
---	-----------------------------------

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ANNEX 3

Ruhusa Ya Mlezi / Mzazi Kwa Kijana Wako Kushiriki Utafiti wa PhD

Kichwa Cha Somo: Haki Ya Afya Ya Uzazi Na Kujamiiana Pamoja Na Mwingiliano Wa Makundi Yaliyo Pembezoni Nchini Tanzania.

Jina langu ni Virpi Mesiäislehto, Mimi ni mtafiti mshiriki katika Chuo Kikuu cha Dar es Salaam na mwanafunzi wa PhD katika Chuo Kikuu cha Jyväskylä nchini Finland. Ninafanya kazi chini ya usimamizi wa Dr Richard Sambaiga kutoka Idara ya Soshologia katika Chuo Kikuu cha Dar es Salaam. Utafiti huu unafanywa kwa njia shirikishi. Ina maana kwamba ili kupata taarifa kuhusu kundi fulani la watu, wanapaswa pia kushirikishwa kadiri iwezekanavyo. Utafiti unazingatia kanuni hii: **"Usiseme lolote kuhusu watu fulani bila kuwashirikisha".** Inaeleweka kuwa maarifa sahihi zaidi na maalum yanaweza kupatikana kama watu watashirikishwa katika utafiti unaowahusu.

Kabla ya wewe na mtoto wako kuamua kama atakuwa sehemu ya utafiti huu ni muhimu kuelewa kwa nini ninafanya utafiti huu na unahusisha nini. Tafadhali soma waraka huu kwa makini. (Mtoto wako atapokea fomu ya ridhaa yake mwenyewe). Ninakuhimiza kujadiliana na mtoto wako kuhusu utafiti huu. Kama mtoto wako ana maswali kuhusu utafiti, jisikie huru kuniuliza.

Dhumuni

Dhumuni la utafiti huu ni kuelewa changamoto ambazo vijana wa kike wenye ulemavu, walio katika mwingiliano wa changamoto za umri, jinsia na ulemavu, wanazokutana nazo kuhusiana na upatikanaji wa taarifa na huduma kuhusu haki ya afya ya uzazi Tanzania. Utafiti huu umegawanywa katika tafiti ndogo ndogo tatu. Utafiti huu ambao mtoto wako atashirikishwa unadhamiria kupata majibu ya swali hili pana: Kuna mapungufu gani yaliyopo katika utoaji wa huduma zinazokidhi kuhusu afya ya uzazi na kujamiiana kwa walio pembezoni na walio katika mwingiliano wa changamoto za umri, jinsia na ulemavu?

Ili kupata taarifa hii kupitia utafiti huu na kutoa taarifa zitakazozalishwa na vijana wenyewe wenye ulemavu itaimarisha uelewa wa hali wanayokutana nayo vijana wa kike wenye ulemavu nchini Tanzania. Utafiti huu utatoa sauti kwa kikundi hiki cha watu na kusaidia kuunda sera jumuishi zaidi kwa watu wenye ulemavu. Lengo la utafiti huu ni kuwajengea uwezo watu wenye ulemavu kuwafanya waelewe kwamba sauti zao zinahitaji kusikika na kwamba wana taarifa muhimu zinazoweza kunufaisha tafiti za kijamii, tafiti kuhusu ulemavu na jamii kwa ujumla.

Utaratibu

Kama utatoa ruhusa kwa mtoto wako kushiriki, atajiunga mara mbili katika majadiliano ya kundi yatakayodumu kwa saa mbili ambapo atakuwa sehemu ya majadiliano ya kikundi na kushiriki shughuli za kikundi zinazofaa kwa umri wake na aina ya ulemavu. Majadiliano yatakuwa juu ya changamoto ambazo anakutana nazo katika upatikanaji wa taarifa na huduma kuhusu haki ya afya ya uzazi na kujamiiana. Kama wewe na mtoto wako mtakubali kushiriki katika utafiti huu, bado anaweza kuacha kushiriki wakati wowote na kukataa kujibu maswali au kushiriki katika shughuli yoyote.

Usiri

Majibu yote ambayo mtoto wako atatoa yatakuwa siri. Ili kupunguza hatari ya siri kuvuja, jina la mtoto wako halitaunganishwa na chochote atakachosema wakati wa utafiti. Nitakapoandika na kuwasilisha matokeo ya utafiti huu sitatumia jina la mtoto wako au taarifa yake yoyote binafsi. Taarifa zote zitakazotolewa na mtoto wako zitakusanywa kwenye huduma ya mtandaoni inayofungwa na neno la siri ambalo linatambuliwa na mimi tu. Hakuna taarifa ya utambulisho itakayohusishwa na majibu yaliyokusanywa kutoka kwa mtoto wako.

Tahadhari

Hakuna hatari ya kimwili kwa mtoto wako kushiriki katika utafiti huu, hata hivyo, baadhi ya maswali yanaweza kumfanya mtoto wako asijisikie vizuri. Ikiwa mtoto wako atapata wasiwasi wakati wowote wa utafiti, hatatatakiwa kujibu au kushiriki katika shughuli hiyo ya utafiti. Mtoto wako anaweza kuacha kushiriki utafiti huu wakati wowote. Ukiukwaji wa siri ni hatari kwa utafiti wote, ni kipaumbele changu cha juu kabisa kupunguza hatari hiyo.

Faida

Hakuna faida binafsi kwako au kwa mtoto wako kwa kushiriki katika utafiti huu. Hata hivyo, kama matokeo ya utafiti, haki ya afya ya uzazi na kujamiiana ya vijana wenye ulemavu nchini Tanzania zinaweza kutarajiwa kuboreshwa na sauti ya vijana wenye ulemavu kusikilizwa kwa sauti kubwa.

Fidia / Malipo

Hakuna malipo yatakayotolewa kwa mtoto wako. Hata hivyo, mtoto wako atapatiwa chai na vitafunwa na fidia ya gharama za usafiri. Kama mtoto wako anahitaji usaidizi maalum kutokana na ulemavu wake, kama mkalimani wa lugha ya ishara, msaada utatolewa ili kuhakikisha ushiriki wake kikamilifu.

Haki

Ushiriki katika utafiti huu ni kwa hiari kabisa. Una haki ya kusitisha ushiriki wa mtoto wako katika utafiti huu au kujiondoa wakati wowote katika utafiti huu bila adhabu yoyote au kupoteza fidia unazostahili. Mtoto wako ana haki sawa ya kusitisha ushiriki au kujitoa katika utafiti wakati wowote.

Maswali

Wewe na mtoto wako mnaweza kuuliza maswali kuhusu utafiti huu wakati wowote, sasa au baadaye, kupitia namba yangu +255766645103 au barua pepe virpi.mesiaislehto@jyu.fi

Kama una maswali yoyote au wasiwasi juu ya atkaavyotendewa mtoto wako katika utafiti huu usisite kuwasiliana na Idara ya Soshologia katika Chuo Kikuu cha Dar es Salaam, Dkt. Richard Sambaiga +255767643600 au barua pepe richsambaiga@gmail.com

Kama utaamua kwamba mtoto wako anaweza kushiriki katika utafiti huu, tafadhali weka sahihi na tarehe hapa chini. Nitawapa nakala ya fomu hii uhifadhi kumbukumbu yako kwa baadaye.

Jina la mtoto kwa herifi kubwa

Jina la Mzazi / Mlezi (Herufi kubwa)	Tarehe
---	------------------------------------
Sahihi au kidole gumba (Mzazi / Mlezi)	Tarehe
---	------------------------------------
Jina la Shahidi (Herufi kubwa)	Tarehe
--	---------------------------------
Sahihi au kidole gumba (Shahidi)	Tarehe
--	---------------------------------

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ANNEX 4

Adolescent assent to participate in a PhD research study

Study title: Sexual and reproductive health and rights at the intersection of vulnerabilities in Tanzania

My name is Virpi Mesiäislehto, I am an associate researcher at the University of Dar es Salaam and a PhD candidate at the University of Jyväskylä in Finland. I am working under the supervision of Dr. Richard Sambaiga from Department of Sociology in the University of Dar es Salaam. I want to ask you if you would like to be a part of this study.

What is a research study?

It is when people like me collect a lot of information to understand better a certain topic. This letter tells you about my study so you can decide if you want to be part of it. Before you decide you can talk to your parent or guardian or anyone else about it. if you have any questions about the research just ask me.

Why am I doing this study?

This study is done so that Tanzanian children and youth with disabilities would have a healthier and better life. It is also done so that adolescents with disabilities like you could give important knowledge about the life of adolescent. I would like to understand the lives of youth with disabilities better through this study with your help. I also hope that I can learn much from you and your information in this study will help that there will be more knowledge on youth like you. This study does not have anything to do with school.

Why am I talking to you about this study?

I am asking many adolescents to help and take part in this study. I am asking you to join because this study is about girls between the age 10-19 that are living with a disability and you are in that range.

What will happen if you are in this study?

If you agree to be in this study and your guardian says it is ok, you will be a part of a group of girls where we will discuss issues related with sexuality, reproductive health and your rights. We will also talk together about how have you gotten information about sexuality and reproduction and how easy is it for you to access reproductive health services. We might even read stories and talk about them together. If you and your guardian agree that you can participate, you can refuse to answer or participate at any time.

Will good things happen from being in this study?

You might enjoy being part of the group discussions as we try to make them comfortable and fun. However, to you personally you will not get any material benefit. However, you might feel good afterwards as you have been able to provide information that will be useful to the youth in Tanzania and those with disabilities.

Are there things you might not like about being in this study?

Some of the topics that we will discuss might make you feel uncomfortable. Some of the activities might feel difficult. if that happens you can skip that topic or activity or stop participating in the study. If you have any concerns or questions you can contact your parent or guardian, me or the research assistant before you take part in the study, during the study or after.

Who will know that you are in this study?

The other group members, you, your guardian, me and the research assistant are the only ones knowing that you are in the study. When I write the report about this research I will not use your name or any personal information about you.

Will you get paid for being in this study?

No, you will not get any money from this study but I will provide you a tea and a snack, as well as compensate for your travel cost.

Do you have to be in this study?

No! Research is something you only do if you want to. Nothing will happen if you don't want to be in this study. You can just tell me. Even if your parent has allowed you to participate, you can still say no. You can also change your mind later, if you first say yes but then you don't want to be a part of the study anymore.

Do you have any questions?

You can ask questions about this study, now or later, any time you want. You can talk to me, your parent or who you choose to. I can be reached at +255766645103 or by e-mail virpi.mesiaislehto@jyu.fi.

If you would like to be in this research study please say so now.

Write the signature here __________________________ *to document that the adolescent received this information*

*Write the signature here*___________________________ *to document that the adolescent has been able to answer these questions. If she is not able to answer a question, repeat the information in the text above.*

1) *Why this study is conducted?*
2) *Why are you asked to participate?*
3) *What happens in this study?*
4) *What will happen if you do not want to be in the study?*
5) *What can you do if you feel uncomfortable during the study?*
6) *What will you get from this study?*
7) *What will you do if you have some questions about this study?*

If you know that you want to be a part of the study, please sign and date below. I will give you the copy of this form to keep for your future reference.

Child's name in capital letters

Child's signature or thumb print Date

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Witness' name in capital letters Date

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Witness' signature or thumb print Date

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ANNEX 5

Ridhaa Ya Vijana Kushiriki Katika Somo La Utafiti Wa Phd

Kichwa Cha Somo: Haki Ya Afya Ya Uzazi Na Kujamiiana Pamoja Na Mwingiliano Wa Makundi Yaliyo Pembezoni Nchini Tanzania.

Jina langu ni Virpi Mesiäislehto, Mimi ni mtafiti mshiriki katika Chuo Kikuu cha Dar es Salaam na mwanafunzi wa PhD katika Chuo Kikuu cha Jyväskylä nchini Finland. Ninafanya kazi chini ya usimamizi wa Dr Richard Sambaiga kutoka Idara ya Soshologia katika Chuo Kikuu cha Dar es Salaam. Ninataka kukuuliza ikiwa ungependa kuwa sehemu ya utafiti huu.

Somo la utafiti ni nini?

Ni pale watu kama mimi wanapokusanya taarifa nyingi ili kuelewa vyema mada fulani. Barua hii inakueleza juu ya utafiti wangu ili uweze kuamua kama unataka kuwa sehemu ya utafiti huu. Kabla ya kuamua unaweza kuzungumza na mzazi wako au mlezi au mtu mwingine yeyote kuhusu hilo. Kama una maswali yoyote kuhusu utafiti usisite kuniuliza.

Kwa nini ninafanya utafiti huu?

Utafiti huu unafanyika ili watoto na vijana wa Tanzania wenye ulemavu waweze kuwa na afya na maisha bora zaidi. Pia utafiti unafanyika ili vijana wenye ulemavu kama wewe waweze kutoa taarifa muhimu kuhusu maisha ya vijana. Ningependa kuelewa maisha ya vijana wenye ulemavu kiundani kupitia utafiti huu kwa msaada wako. Pia nina matumaini kwamba ninaweza kujifunza mengi kutoka kwako na maelezo yako katika utafiti huu yatasaidia na kutakuwa na uelewa zaidi juu ya vijana kama wewe. Utafiti huu hauhusiani na shule.

Kwa nini ninazungumza na wewe kuhusu utafiti huu?

Ninawaomba vijana wengi kusaidia na kushiriki katika utafiti huu. Ninakuomba ujiunge kwa sababu utafiti huu ni kuhusu wasichana wenye umri kati ya miaka 10-19 ambao wanaishi na ulemavu na wewe upo katika kudi la umri huo.

Nini kitatokea ukishiriki katika utafiti huu?

Kama utakubali kuwa katika utafiti huu na mlezi wako akasema ni sawa, utakuwa sehemu ya kikundi cha wasichana ambapo tutajadili masuala yanayohusiana na haki zako za afya ya uzazi na kujamiiana. Tutazungumza pia pamoja juu ya jinsi ulivyopata taarifa kuhusu ujinsia na uzazi na jinsi gani ilivyo rahisi kupata huduma za afya za uzazi. Tunaweza hata kusoma hadithi na kuzizungumzia kwa pamoja. Ikiwa wewe na mlezi wako mtakubali kwamba unaweza kushiriki, bado unaweza kukataa kujibu maswali au kuacha kushiriki wakati wowote.

Je, mambo mazuri yatatokea kwa kushiriki katika utafiti huu?

Unaweza kufurahia kuwa sehemu ya kikundi cha majadiliano kwani tunajitahidi kuyafanya yawe mazuri na ya kufurahisha. Hata hivyo, kwako binafsi hutapata faida yoyote ya nyenzo. Hata hivyo, unaweza kujisikia vizuri baadae kwamba umeweza kutoa taarifa ambazo zitakuwa msaada kwa vijana nchini Tanzania na hasa wale wenye ulemavu.

Kuna mambo ambayo huenda usingependa yawepo katika utafiti huu?

Kuna baadhi ya mada ambazo tutazijadili na zinaweza kukufanya usijisikie vizuri. Baadhi ya shughuli zinaweza kuwa ngumu. Kama hilo ilitokea unaweza kuiruka mada hiyo au shughuli au kusitisha ushiriki katika utafiti. Ikiwa una matatizo yoyote au maswali unaweza kuwasiliana na mzazi au mlezi wako, mimi au msaidizi wa utafiti kabla ya kushiriki katika utafiti, wakati wa utafiti au baada.

Ni nani atakayejua kuwa unashiriki katika utafiti huu?

Ni wajumbe wengine wa kikundi, wewe, mlezi wako, mimi na msaidizi wa utafiti ndio pekee wanaojua kuwa unashiriki katika utafiti. Nitakapoandika ripoti kuhusu utafiti huu sitatumia jina lako au taarifa zozote binafsi kuhusu wewe.

Je, Utalipwa kwa kushiriki katika utafiti huu?

Hapana, hautalipwa pesa yoyote kutokana na utafiti huu lakini nitatoa chai na vitafunio, na pia kulipa fidia gharama zako za usafiri.

Je, ni lazima kushiriki katika utafiti huu?

Hapana! Utafiti ni kitu unachofanya ikiwa tu unataka. Hakuna kitakachotokea ikiwa hutapenda kushiriki katika utafiti huu. Unaweza kuniambia tu. Hata kama mzazi wako amekuruhusu kushiriki, bado unaweza kusema hapana. Unaweza pia kubadilisha mawazo yako baadaye, ikiwa umekubali kushiriki lakini ukaghairi kuendelea na utafiti tena.

Je, Una swali lolote?

Unaweza kuuliza swali kuhusu utafiti huu, sasa au baadaye, wakati wowote unaotaka. Unaweza kuzungumza na mimi, mzazi wako au yoyote utakamyechagua. Ninaweza kupatikana kwa namba **+255766645103** au kwa barua pepe **virpi.mesiaislehto@jyu.fi**.

Ikiwa ungependa kushiriki katika utafiti huu, tafadhali sema sasa.

Weka sahihi hapa ___________________________ kuthibitisha kwamba kijana amepata taarifa hii.

Weka sahihi hapa ___________________________ kuthibitisha kwamba kijana ameweza kujibu maswali haya. Ikiwa yeye hawezi kujibu swali, rudia taarifa ya hapo juu.

1) Kwa nini utafiti huu unafanyika?

2) Kwa nini unaombwa kushiriki?

3) Nini kitatokea kutokana na utafiti huu?

4) Nini kitatokea ikiwa hutaki kushiriki utafiti huu?

5) Unaweza kufanya nini ikiwa hujisikii vizuri wakati wa utafiti?

6) Utapata nini kutokana na utafiti huu?

7) Utafanya nini ikiwa una maswali kuhusu utafiti huu?

Ikiwa unajua kwamba unataka kuwa sehemu ya utafiti, tafadhali weka sahihi na tarehe hapa chini. Nitakupa nakala ya fomu hii kwa ajili ya kumbukumbu yako ya baadaye.

Jina la mtoto kwa herufi kubwa. Tarehe

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Sahihi ya mtoto au kidole gumba

Jina la Shahidi kwa herufi kubwa Tarehe

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Sahihi ya shahidi au kidole gumba
