USING GOVERNMENTALITY AND PERFORMATIVITY THEORY TO UNDERSTAND THE ROLE OF SOCIAL ATTITUDES IN YOUNG PEOPLE WITH VISUAL IMPAIRMENT ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH SERVICES

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Abstract

This exploratory study investigates how governmentality enforced by societal attitudes influences performativity of young people with visual impairment (PVI) to/not access sexual and reproductive health services (SRH). To explore this phenomenon, existing data was utilised from a focus group around the sexuality of young PVI with three experts in the field of visual impairment as a starting point. A thematic analysis revealed various challenges that might be encountered by young PVI as they access SRH, e.g. stigma. A Foucauldian discourse analysis builds on these challenges by suggesting that governmentality construed by institutional, macro-level structures (e.g. social attitudes) should not be taken as the only barriers to/not accessing SRH, but young PVI might also employ individual, micro-level decision-making processes (e.g. socially-negotiated rationalities) to/not access SRH. The final theorisation here remains unsettled; actual voices of young PVI need to be located in this ongoing conversation.

Key words: access; governmentality; young people with visual impairment; performativity; sexual and reproductive health services; social attitudes

Introduction

The available literature has shown how hegemonic socio-medical discourses have shaped our social perceptions of young people living with visual impairment (PVI)¹ as asexual, unfit to parent, yet at risk of rape, HIV infection and in need of sexual and reproductive health (SRH) (Mavuso & Maharaj, 2015; Peta, McKenzie, Kathard & Africa, 2016; Peta & Ned, 2019). However, further work is required which investigates how these hegemonic socio-medical discourses in turn shapes the choices, behaviour and conduct (i.e. self-governance) taken by young PVI in accessing (or not) SRH (e.g. performing health-seeking or avoidance behaviours) using post-structural theories such as Foucault's (1991) governmentality and Butler's (1990) performativity theory. In this study, SRH relates to a holistic state of physical, emotional, mental and social well-being in all aspects encompassing both sexual and reproductive health, and not just mere a focus on the absence of disease, dysfunction or infirmity (World Health Organisation, WHO, 2017).

Governmentality

Foucault's 1970s to '80s work around power stands as a comprehensive yet extensive body of knowledge in how power is negotiated in society and how that affects a group or individuals' decision-making and conduct (Dean, 2017). In 1991, Foucault (1991, pp. 108–109) defined his theory of governmentality as:

The ensemble formed by institutions, procedures, analysis and reflections, calculations, and tactics that allow the exercise of ...power that has the population as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument.

In other words, Foucault $(1991)^2$ was interested in amongst other things, how the subtle social (e.g. government rationality) and individual control mechanisms (e.g. a fallacious belief of a self-regulating subject) used to govern people's behaviour, translates into how they govern themselves (Holmes, Gastaldo, O'Byrne, & Lombardo, 2008). Dean (1999) further broke down governmentality into 'govern' and

¹ That is, those living with low to full visual impairment (Kapperman & Kelly, 2013).

² Foucault's (1991) concept of governmentality has been extensively interpreted and applied in many contexts such as gender and sexuality studies (Brown & Knopp, 2014), education policy studies (Fimyar, 2008) and many other disciplines like science and technology (Introna, 2016). Due to space constraints, I cannot unpack the various interpretations of the theory and it implications. Keen readers of governmentality are encouraged to read Dean (1991) for a broader introduction into governmentality theory.

'mentality' or mentalities of governing to suggest *how* and *what* those who are governed think about the definitions, conditions, choices, restrictions and opportunities placed upon them by others in certain situations. For instance, the compulsory able-bodiedness (i.e. over-representation of able-bodiedness as the norm of health and fertility) and heteronormativity (i.e. the preference of hetero-masculine and hetero-feminine roles, identities and relationships) perpetuated in most sexuality education programmes raises serious questions around who should reproduce (and with whom). In short, governmentality asks, "who can govern; who can be governed; what is to be governed; and how" (Walters & Haahr, 2005, p. 290). In this study, Foucault's (1991) theory of governmentality is used to consider how the discursive use of language and entrenched social attitudes (i.e. dominant socio-medical discourses) about the SRH of PVI not only affects their self-governance (e.g. self-knowledge), but also shapes their self-conduct (e.g. uptake of health-seeking versus avoidance behaviours).

Performativity

Judith Butler (1990), a philosopher and feminist theorist, was keen on understanding how everyday roles, decisions and performances of individuals are impacted by social norms or habits. Drawing much influence from Foucault's work, Butler (1993, p. xii) builds on Foucauldian discourse in her definition of performativity as "that reiterative power of discourse to produce the phenomena that it regulates and constraints". While relying on Foucault's (1970s-80s) work around subjects, discourses and consequences being created through dominant discourses, e.g. sane/insane, fertile/infertile, desirable/undesirable, Butler (1990) was mostly interested in the social construction of gendered subjectivities (e.g. hetero-masculine and hetero-feminine subjects) has consequences in power relations (e.g. gender domination in patriarchal societies). It should be noted that Butler (1990) saw these subjects as possessing the ability to subvert social constructions of themselves (e.g. through gender non-conformity). Butler's (1990) performativity theory can be applied to disability studies in seeing how repeated, idealised performances such as the gatekeeping of the preferred image of the family institution, namely that of an able-bodied, hetero-sexual couple producing ablebodied children results in conventional norms which could later become the evaluative benchmarks as to who should reproduce (and with whom). Much like Foucault's (1991) governmentality theory, Butler (1990) was interested in how we are positioned in different ways affects what we can/not say and what we can/not do³. Therefore, in this study, Butler's (1990) performativity theory will be used to consider how hegemonic sexual discourse about the SRH of PVI affects their performativity (e.g. individual conformity to perceived social norm) about the SRH of PVI (e.g. disinterestedness in sex).

Disability and sexual and reproductive health

In order to understand the workings of hegemonic socio-medical discourses into social attitudes about the sexuality of young PVI, it is crucial to unpack the historical understandings of disability (Grue, 2011). Globally, the shifting experiences of disability have largely been due to steadfast activism behind the 1960s disability movements from defining disability from a medical model that was proccupied in pathologizing the person's impairment as something to 'fix' (Stiker, 2019). As a result of the movement's advocacy, disability came to be regarded as a social and human rights agenda, calling for the removal of barriers in access to information, movement, employment, education – and SRH for persons living with disabilities (PWD) (UN Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2009)). Yet, for a long period and still today, PWD were deprived of their right to reproduce (see unwanted sterilisations in Nazi Germany in Rosenberg (2016)). PWD were denied access to SRH in state and local healthcare centres (Burke, Kébé, Flink, van Reeuwijk & le May, 2017; Karimu, 2017; Badu, Gyamfi, Opoku Mprah, & Edusei, 2018). Furthermore, PWD are still largely characterized as heterosexual (Chappell, 2015, 2016 and 2019), and "expected to be impotent and uninterested in sex" (Foulke & Uhde, 1974, p. 199).

However, international conventions like WHO and the UN have worked tirelessly to enact treaties that recognise the rights of PWD access to SRH and their right to have children (see Article 25 of the UNCRPD

³ It should however be noted that both Foucault (1991) and Butler (1990) did not see the relations of power working as top down, vertical processes meted against insensible individuals with fixed identities. In fact, both theorists conceived of reflexive, complicated subjects with fluid identities on multiple and overlapping social categories (e.g. race, gender, class and so on) at any given time. In other words, both Foucault (1991) and Butler (1990) would thereby draw knowledge also from bottom up, horizontal processes (e.g. interactions with others).

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and the UN's Sustainable Developmental Goal 3-5). In other words, international conventions like the UN see PWD access to SRH and the right to have children as a universal human right (WHO, 2017). It is for this reason that the UNCRPD (UN, 2009) views disability as "an evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full participation in society on an equal basis with others" (p. 5). SA is a signatory of the UNCRPD and upholds an anti-discrimination stance within its Constitution's none tolerance of discrimination to reproductive information and services on the basis of disability (Chapter 2, Section 9(3-5), 12(2)(a-c) and 27(1)(a)). Furthermore, the Children's Act 38 of 2005 acknowledges children's rights to information around sexuality and reproduction, with special consideration of children with disabilities in an accessible format given the appropriate age, maturity and understanding of the child (Chapter 2, Section 38).

Yet despite the adoption of social justice legislative frameworks, recent studies show that young PVI are still confronted by unwelcoming attitudes when accessing SRH in public healthcare settings (McKenzie, 2013; Rugoho & Maphosa, 2017; Badu et al., 2018). In addition, their right to reproduce is often frowned upon as selfish towards their parents and unconcerned that they will give birth to a child who is also visually impaired (Peta et al., 2016; Burke et al., 2017; Peta & Ned, 2019). However, scientific evidence shows genetic disabilities occur in small proportions of births, and so for child-bearers with disabilities (United Nations Population Fund, UNFPA, 2007). Notably, Mavuso and Maharaj (2015) conducted a study on the experiences of physically and visually impaired persons of reproductive ages (27 to 46 years) access to SRH at a residence for PWD in Durban, Kwa-Zulu Natal province. In the study, the researchers found male participants reported their experiences as discouraging due to the poor treatment of nursing staff as evidenced by one of the male respondents (p. 83):

Men tend to stay away from sexual health services because you find that most nurses are females and they do not have a way of talking to us in the manner that encourages us to visit health services. For people with disabilities it is worse than people without disabilities. Imagine if a man who is not disabled gets scolded like that and is spoken to in an irresponsible fashion – how much worse it is if I am disabled (P5, male).

Much like the resistance of the men above, the women in the study reported not wanting to talk about sex with nurses in fear that they will be perceived as sexually active. The fear of discussing a taboo subject like sex prevented the women from taking condoms as one of the female participants maintained (p. 83):

Sometimes you will see condoms. I would like to take them, but I'm afraid of what the people around me might think or say. You feel ashamed because you are disabled and what would people say. You fear that they would make assumptions about my disability and question if I am also sexually active. I have that fear and it prevents me from taking them. Then what happens is I end up not taking the condoms (P4, female).

Governmentality, performativity and sexual and reproductive health

Foucault's (1991) work on power and governmentality maintains that social attitudes informed by social institutions like medicine create discourses, which later in the form societal attitudes, influence the access (or lack thereof) of some individual's right to organized state institutions as clinics and hospitals. Yet Foucault (1991) pointed to another key aspect to consider in his concept of governmentality that operates beyond institutional, structural and macro-level. That is, the specific, socially negotiated micro-mechanisms individuals employ to regulate themselves and others. Governmentality is linked to neoliberal capitalist notions of individuals making rational, autonomous decision-making within rigid regimes of disciplinary power and knowledge (Foucault, 1997). In other words, individuals formulate knowledge, identities and agency in relation to existing discourse and social norms which they use to regulate their own and other's behaviour (e.g. rationality behind their own and others risk-taking versus health-seeking behaviours). To demonstrate this, a woman in a rural setting may/not take condoms after a HIV and wellness seminar based on the knowledge and instilled fear that other women in the community may perceive her as HIV-infected. As Foucault (1997, p.291) puts it, the subject constitutes itself in an active fashion through the practices of self, these practices are nevertheless not something invented by the individual himself [sic]. They are models that he finds in his culture and are proposed, suggested, imposed upon him by his culture, his society and his social group.

Therefore, studies like Mavuso and Maharaj's (2015) study at first glance, seem to suggest in their findings that there is a close relationship of performance of health-seeking or avoidance behaviours employed by PWD tied to the governing rationalities of healthcare providers (e.g. poor treatment by nursing staff), which regulate and shape PWD conduct when deciding (or not) to access SRH. I however contend that this is one part of the explanation whereas the individual, yet socially mediated decision-making by PWD, are overlooked and taken for granted. In other words, there is still missing theoretical knowledge of how the individual assumptions, dispositions, mentalities and choices influences the decision-making of young PVI to/not access SRH or their thinking around their right to reproduce. As Brown and Knopp (cited in McKie, Davies, Nixon, & Lachowsky, 2019) point out in their research on governmentality and gay men's sexual practices: "Research cannot focus only or even primarily on the objects that gaze, but also consider the embodied gazers themselves as implicated in governmentality. The gay community reminds us that knowledge is produced bottom up, as well as top down" (p. 107). Using Butler's (1990) performativity theory, we can further theorise how social norms may influence young PVI performativity in relation to/not accessing SRH (e.g. opting for avoidance behaviours like not taking condoms based on perceived social judgement). To my knowledge, there are currently no available studies in the SA context which have investigated how governmentality enforced by societal attitudes influences performativity of young PVI access to SRH, or how that influences their right to reproduce.

Methods

Project description

The European Union (EU), in partnership with the South African Department of Higher Education (DHET), granted the funding of R 9.925 million (559 776 Great Britain Pounds) to the University of Pretoria (UP) towards the call to implement inclusive education policy in the area of LVI. To do this, UP set up the following objectives for 2016 to 2021: (a) Initiate national research with selected full-service, special needs schools, teachers, stakeholders and experts; (b) Develop an advanced postgraduate diploma in Visual Impairment Studies (DipVIS); (c) Create open education resource materials for students enrolled in the DipVIS; and lastly; (d) Establish a national hub for visual impairment studies in the form of a Centre for Visual Impairment Studies. The ethical clearance (UP 17/06/01 Ferreira 17-003) was approved by University of Pretoria's Research Committee in line with its ethical guidelines of obtaining informed consent, voluntary participation with no negative consequences of declining, and confidentiality of participants' identifying information. The study utilises qualitative data obtained from a focus group interview with three of the experts contributing to the material development of the DipVIS. No financial incentive was provided for participation in the study.

Sampling

As part of a material development workshop, the participants were invited to a writing retreat to conceptualise their modules for the DipVIS. The sampling technique was purposive sampling based on their years of experience in working with young PVI. The invited experts included a head of a disability unit, a low vision/blind support specialist, and a high school teacher at a school for young PVI. All three experts were female – see Table 1. The analysis that followed from the co-generated data by the researcher and experts resulted in two emerging themes to be discussed and interpreted in the finding's section.

Preferred pseudonym	Focus group interview (FGI) or individual interview (II)	Race and sex	Occupation	Type of organisation	Years of working with LVI
К	FGI	Black female	Head of disability unit	Higher academic institution	10 years
С	FGI	White female	Teacher at a school for LVI	Secondary high school	5 years
R	FGI	White female	Low vision and blind support specialist	Private company	54 years

Table 1: Participants' characteristics

Data collection methods

Qualitative data collection and analysis methods were followed in this study. The experts were invited for an interview in a focus group conducted by myself (a PhD candidate and material developer) to discuss issues around the sexuality of young PVI. The interview lasted over 1 hour and conducted in English as preferred by all three participants. The unstructured interview questions were formulated from both the available literature as well as the research findings in the larger study following teacher's concerns about the need to address the sexuality of young PVI. The entry and barriers to access of SRH become a prominent topic within the discussion.

Data management and analysis

The focus group was audio-recorded for authenticity and later written transcripts were obtained from the audio-recordings. Membership checking was performed by sending the participants the written transcripts to check and confirm the accurateness of what was said in the interview. In terms of management of the data, the audio-recordings and written transcripts will be stored and destroyed after 10 years in a GoogleDrive file and flash drive in which only the project leader, the 3 experts and myself will have access. After preliminary analysis, participants were sent copy of the codes and emerging themes to confirm the trustworthiness of the findings, which they confirmed were valid. Data were analyzed using Braun and Clarke's (2006) six steps of thematic analysis: (1) immerse yourself with the data, (2) create initial codes, (3) search for emerging themes, (4) review emerging themes, (5) identify and name themes with consultation of the literature and theoretical framework, and finally (6) write-up the report.

Findings

The following two themes emerged from the study and interpreted below: (1) Challenges in accessing SRH by young PVI, and (2) Decisions taken to have children by young PVI.

(1) Challenges of accessing SRH by young visually impaired people

Various structural and macro-level challenges in accessing SRH were identified by the three experts working with young PVI. Below, a presentation of generated codes and substantiated quotations are presented.

Access to information and advice on family planning

The first concern was around the accessibility of information and advice on family planning with young PVI embedded as the primary recipient:

'C' (white female, teacher at a school for LVI): My first thought with the topic was that accessibility and access to information.

'R' (white female, low vision and blind support specialist): Advice.

'C' (white female, teacher at a school for LVI): Advice, contraception, family planning, genetic counselling is not easy to get access.

Difficulty in initiating conversations with parents

One of the respondents referred to the difficulty experienced by young PVI in bringing up sexuality topics with their parents:

'R' (white female, low vision and blind support specialist): How to deal with sexual issues with their parents, I think that's a big thing isn't it?

Limitation in movement resulting in dependency on others

Due limitations in movement, respondents expressed concerns of young PVI ability to access SRH given their dependence on others for mobility:

'C' (white female, teacher at a school for LVI): It's already tricky if you can see, it is trickier when you can't [see], you are more dependent on people. That dependence on them to help and...

'R' (white female, low vision and blind support specialist): And your limited to the people you can talk to if you don't have independence by being able to walk alone to a clinic.

'C' (white female, teacher at a school for LVI): Ja, travel alone, you can't drive yourself to a place.

Critical attitudes and lack of confidentiality due to small class sizes

Respondents pointed to critical attitudes by untrained healthcare providers in sensitivity in handling confidential information. In addition, respondents reported confidentiality is more likely to be violated given the small class in special needs schools:

'R' (white female, low vision and blind support specialist): If you think you've got HIV for instance you need to go and have some confidential discussions with somebody, they can't travel alone, they've got to go to somebody who may not be trained to deal with the situation like that and may even be very critical.

Conversation continues...

'C' (white female, teacher at a school for LVI): Ja at the schools, I mean my experience is ... [it] is really difficult privacy because [it] is a small school and ... you know we are their world in a big sense and we are the people they ask. And then, if you don't respect their privacy and you tell the other person, as people do ... then they have no privacy is just really bad.

Stereotypes about PVI sexual ability, ability to reproduce, attraction, raising a child

During their conversational exchange, respondents identified a number of stereotypes about the sexual ability, attraction and the capability of PVI to raise children:

'C' (white female, teacher at a school for LVI): Ja and there are lots of stereotypes ...

'R' (white female, low vision and blind support specialist): You can't have babies...

'C' (white female, teacher at a school for LVI): Ja, they literally think that blind people can't or...

'R' (white female, low vision and blind support specialist): ... how do blind people make love? (laughs)

'C' (white female, teacher at a school for LVI): Don't you switch off the lights?

'R' (white female, low vision and blind support specialist): You can't see your partner ...

Active discouragement of persons with visual impairments from reproducing

Noteworthy, respondents maintained that young PVI are sometimes actively discouraged against reproducing by healthcare providers for fear that they will produce visually impaired children:

'K' (black female, head of university disability unit): Like I'm surprised that it doesn't ... because I got it when they get to university ... because we have a couple, both blind, both of them ... that's how they met. And when they go for family planning, the nurses say like, "why" and yet they are a couple going together. So they ask the male to come in first to say, "You can't do this to her, you going to have blind babies." You know...that's the perception.

'R' (white female, low vision and blind support specialist): Or you can't have babies, you shouldn't have babies, you can't change the nappies...

Facilitator: So the people make the decisions for them?

'R' (white female, low vision and blind support specialist): Especially the teenagers.

(2) Decisions taken to have children by young PVI

Another emerging theme in the focus group interview were the concerns influencing the decision to reproduce such as the personal experiences of growing up with a visual impairment, socio-economic issues and the individual's personal choice.

Personal experiences of their own lives

The respondents located the personal experiences of living with a visual impairment and relatively adjusting to one's surroundings as a feature that may influence the decision to reproduce:

'C' (white female, teacher at a school for LVI): Yes, it all depends also on how they experience their own lives, so they feel that they're fine and they are adapting, they just feel why can't they have a blind kid, a blind kid is fine.

Socioeconomic issues like poverty, dependence on parents and both parents being blind

Respondents saw the consideration of socio-economic issues such as living in poverty as a complicating aspect especially when two PVI decide to have children:

'C' (white female, teacher at a school for LVI): It tends, you know where I think there is more issues, if the child comes from a home where there is poverty. So I mean there's already an issue if you sighted and you're poor, and you having kids, and as a teacher, I can say that I am really concerned when they are poor and they're blind and their partner is blind because in a way you thinking, maybe in just making assumptions, because how am I to judge now that that life isn't an okay life. It is maybe a burden financially on society, or burden that they going to ask for more help from parents...is not necessarily a life less worthy of living, but you are concerned because life is going to be tough, is going to be touch especially if they're both blind, and they both poor. Conversation continues...

'C' (white female, teacher at a school for LVI): And now you're blind ... and you have a baby. So as a teacher I think that's where it's difficult ... what [to] do [or] say you know and how much are you starring the conversation.

Personal choice

Ultimately, respondents felt that the final decision to have children rests upon the PVI or couple with the desired wish:

'R' (white female, low vision and blind support specialist): But it still comes down to choice. **'C' (white female, teacher at a school for LVI):** That's the thing, that's their choice.

Discussion

The study aimed to explore how dominant socio-medical discourses about the sexuality of young PVI (e.g. young PVI being assumed to be celibate, impotent and disinterested in sex) in turn shapes the choices, conduct and performances taken by young PVI to/not access SRH. One of the findings, namely the challenges faced by young PVI in accessing SRH echoed recent African studies by Mavuso and Maharaj (2015), Burke et al. (2017) and Badu et al. (2018), identifying structural, macro-level barriers in PWD accessing SRH, such as inaccessible information, critical attitudes and active discouragement by healthcare providers. In fact, the finding resonates with the majority of studies in the field and international conventions (e.g. UNCRPD) taking up a broader institutional, macro-level approach in advocating for equal access of PWD to SRH (UNFPA, 2007; Rohleder, Swartz, Schneider, & Eide, 2012; McKenzie, 2013; Peta et al., 2017; WHO, 2017). This broader approach aligns with the social and human rights model of disability, which elucidated earlier, calls for the removal of structural, macro-level barriers in amongst others information, housing, education, movement and SRH for PWD to participate equally in society as equal citizens (UN, 2006). According to this broader approach, negative social attitudes and discrimination within organized state institutions like public hospitals still create attitudinal and environmental barriers for PWD to access SRH (UN, 2006; Mavuso & Maharaj, 2015; Peta & Ned, 2019). However, this study pointed out that there is still further research needed to generate theoretical knowledge which considers how individual micro-level decision-making processes (i.e. self-governance) employed by young PVI influences their access (or not) to SRH amidst the prevailing broader structural, macro-level challenges.

To carry out this theoretical examination, the study relied on the post-structural theories of Foucault's (1991) governmentality and Butler's (1990) performativity theory. According to Foucault (1991), governmentality relates to how the broader social (e.g. medical discourse creating subjects and consequences as in ablebodied/disabled, sexual/non-sexual, needs SRH/does not require SRH) together with individual control mechanisms (e.g. the erroneous belief that PWD will draw self-knowledge outside these discourses), in turn shapes their decision-making and self-conduct. In other words, governmentality is interested in how rigid disciplinary knowledge (e.g. medicine) and broader social structures (e.g. attitudes of healthcare workers) will influence the agency of young PVI to perform health seeking versus avoidance behaviours. Butler's (1990) performativity theory was mostly concerned in how socially constructed subjects like gendered subjectivities (e.g. men and women), perform certain roles and behaviours (e.g. manhood and womanhood) based on what is socially expected of them in a given situation (e.g. birthing children in marriage). In this case, Butler (1990) studied the aspects leading to individual conformity by gendered subjectivities (e.g. achieving personhood through marriage and having children). One of the findings of this study was the respondents suggesting that young PVI may rely on a number of aspects in deciding to/not have children. For example, respondents suggested young PVI might rely on their own experience of living with the visual impairment, or their current socio-economic stability to decide to/not have children.

From the above findings, the study suggests that despite the constant macro-level challenges attempt to devalue the SRH of young PVI, they may in turn resist these efforts in the form of self-management strategies such as relying on their own intimate experiences of living with a visual impairment to construct their needs for SRH, or their right to reproduce. In Foucauldian discourse analysis (Rose, 1996), although young PVI may experience unwavering macro-level challenges as imposing oppressive disciplinary knowledge on their self-governance and conduct (e.g. hegemonic socio-medical discourses as constructing them as asexual and disinterested in sex), young PVI may create new technologies of self, namely self-governing capabilities when constructing their own SRH, or desires to have/not have children. Foucault (1988, p. 18) defined technologies of the self as techniques that

[...] permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality.

Rose (1996), drawing on Foucault technologies of self, proposed that freedom as a central concept in the self-governing capabilities of enterprise and autonomy present in the self-regulating abilities of individuals. His insights into the enterprising self extends Foucault's (1991) governmentality theory by suggesting

The enterprising self will make an enterprise of its life, seek to maximize its own human capital, project itself a future, and seek to shape life in order to become what it wishes to be. The enterprising self is thus both an active self and a calculating self, a self that calculates about itself and that acts upon itself in order to better itself (Rose, 1996:154).

Rose's (1996) conceptions of the enterprising self is consistent with Butler's (1990) notions of subversion in her performativity theory. According to Butler (1990), despite the social construction of gendered subjectivities or in this case asexual and unfit to parent young PVI, these subjects possess the will to resist individual conformity to what is expected of them. As the study findings show, young PVI may resist dominant socio-medical discourses about their SRH based on proximal encounters (e.g. intimate experiences of their sexuality) or distal experiences (e.g. seeing other young PVI raising children) to construct their own SRH needs or while deciding to have/or not have children of their own.

Conclusion

The vast majority of literature around access to SRH has been invested in identifying structural, macro-level challenges young PVI face in entering organized state institutions like public healthcare (e.g. poor treatment by healthcare providers) (Mavuso & Maharaj, 2015; Peta et al., 2016; Peta & Ned, 2019). According to the literature, one of the reasons for this is that hegemonic socio-medical discourses suggests young PVI are celibate, unfit to parent and disinterested in sex (Burke et al., 2017; Karimu, 2017; Badu et al., 2018). The sole focus in institutional barriers to young PVI access to SRH was identified as probably informed by the strategic approach of the social, human rights-based model of disability (UN, 2006). However, the study suggested that little is known how dominant socio-medical discourses about the sexuality of young PVI (e.g. young PVI being assumed to be celibate, impotent and disinterested in sex) in turn shapes the choices, conduct and performances taken by young PVI to/not access SRH. To contribute to this gap in knowledge, the study considered Foucault's (1991) governmentality and Butler's (1990) performativity theory. Using Foucault's (1991) governmentality theory, the findings of the study point out that despite the oppressive dominant socio-medical discourses that de-naturalises the SRH of young PVI, young PVI may employ new technologies of self, such as those based on personal experiences of living with a visual impairment when defining their SRH, or when considering to have/not having children. Building on this Foucauldian discourse analysis, Butler's (1990) performativity theory showed that much like socially constructed gendered subjectivities capacity to insubordinate social norms through gender non-conformity, young PVI may also subvert hegemonic socio-medical discourses about their lack of interest in sex or having children by resisting individual conformity to social norms based on their own intimate sexual experiences. A limitation of this study is that data from a focus group interview with experts working with young PVI was used instead of the actual voices of young PVI. Future research should locate the actual voices of young PVI to contribute themselves to this ongoing discussion.

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Disclosure statement

The authors of this paper declare no potential conflict of interest.

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