Invisible men

The social complexities of involving males in biomedical HIV prevention in Eswatini

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LIST OF PUBLICATIONS

Thesis-based publications

Authors' abbreviations
Alfred Khehla Adams (AA), Eileen Moyer (EM)), Agostino Zamberia (AZ), Sarah Day (SD), Fortunate Shabalala (FS), Ndumiso Dlamini (ND), Paul Mangara (PM), Kudzayi Ndlovu (KN), Jacqueline Pienaar (JP).

Chapter 2 is based on the article: '**Adams, Alfred**, and Eileen Moyer. "Sex is never the same: Men's perspectives on refusing circumcision from an in-depth qualitative study in Kwaluseni, Swaziland." *Global Public Health* 10, no. 5-6 (2015): 721-738.

AA designed the study, questionnaires, and collected the data. EM contributed to the data analysis and writing of the manuscript.

Chapter 3 is based on: '**Adams, Alfred K**., and Agostino M. Zamberia. ""I will take ARVs once my body deteriorates": an analysis of Swazi men's perceptions and acceptability of Test and Start." African Journal of AIDS Research 16, no. 4 (2017).

AA designed the study, questionnaires, and collected the data. AZ assisted with data analysis and framing of the manuscript and reviewing it critically.

Chapter 4 is based on: 'Social Complexities of informed consent and assent among young males undergoing voluntary medical male circumcision in Eswatini'. BMJ Global Health 2022;7:e007918

AA designed the study, questionnaires, and collected the data. EM and FS assisted with data analysis. Writing was one by AA and EM.

Chapter 5 is based on: '**Adams, Alfred Khehla**, Sarah Day, Jacqueline Pienaar, Ndumiso Dlamini, Kudzayi Ndlovu, and Paul Mangara. "Towards a context-specific understanding of masculinities in Eswatini within voluntary medical male circumcision programming." Culture, health & sexuality (2021): 1-13.'

AA and SD designed the study and questionnaires. AA collected data with assistance from ND, PM, and KN. AA and SD analyzed the data with AA writing the manuscript. SD and JP assisted with critically reviewing the manuscript.

SUMMARY

Evidence based medicine (EBM), in particular efficacious biomedical technologies discovered through randomized controlled trials (RCTs), have become very powerful tools in shaping global health. Despite this power, which emanates from the availability of funding and the political pressure this funding exerts on global south governments, uptake of these potent medical technologies depends on how these technologies are perceived by their intended users and this is a complex social issue that cannot be solved by availing these technologies.

Following three seminal RCTs in South Africa, Uganda, and Kenya, which showed that voluntary medical male circumcision (VMMC) can relatively reduce HIV transmission from women to men by up to 60%, the World Health Organization (WHO) hailed this as evidence beyond reasonable doubt and recommended that VMMC be implemented in 14 priority countries, including Eswatini. Funding followed suit and targets were set.

The die was cast and the agenda cast in stone. The plan was to circumcise 80% of males in these 14 Sub-Saharan Countries with high HIV prevalence and low coverage of circumcised males such as Eswatini. A few years later, another scientific breakthrough was announced, HIV treatment drugs were found through an RCT to reduce HIV transmission by up to 96%. This was the birth of an HIV intervention to be later known as Test and Start, meaning that all people diagnosed with HIV were linked to treatment as soon as possible despite their CD4 cell count. Just like the VMMC recommendation from WHO, the Eswatini government also introduced Test and Start and one of the main priority target populations were Swazi men.

Drawing on evidence from ethnographic fieldwork, this thesis explored Swazi males' perceptions on VMMC and Test and Start. I aimed to gain an emic perspective on why there was low utilization of these readily available potent biomedical technologies by Swazi males. This thesis is based on four empirical chapters (Chapter 2-5) which were published as

individual manuscripts. The first chapter stated the aims and research questions of the thesis. Since the thesis focused on men, the concept of masculinities served as a fundamental analytical framework. Other important concepts such as government experimentality were discussed in the introduction and the chapter also warns against the remedicalization of the HIV response. This chapter also raised a concern on glossing efficacy and effectiveness of biomedical interventions. In the case of VMMC, with funding from the US government, Eswatini attempted to demonstrate real world effectiveness of VMMC by circumcising 80% of Swazi men in one year. Eswatini had the ideal characteristics of being an experimental field due to its small population, small geographic size, the highest HIV prevalence in the whole world, and relatively well-developed infrastructure. This emergency to circumcise a majority of Swazi males was legitimated by the availability of funds and to save lives in the shortest amount of time possible. In short, Eswatini was a convenient place to produce real world VMMC evidence through intervention. While the supply side was well equipped and organized, there was very low demand for the intervention.

The second chapter investigated men's reactions and perceptions to VMMC. It was clear that older Swazi males were resisting the pressure to get their foreskins removed. The circumcision program was met with widespread resistance by Swazi males and ethnography was used to gather information on this resistance. One of the major factors for this resistance were men's fears and concerns that sex would never be the same post circumcision. Men feared that removing the foreskin would remove sensitive parts, harden the glans and consequently lead to decreased penile sensitivity. This was exacerbated by the fear of adverse events during and after circumcision. Adverse events are a possibility in all surgeries and with circumcision the stakes were too high because this involved an organ which is central to manhood for many Swazi men. This was a threat to the Swazi men's masculinities. Other factors which complicated the uptake of circumcision was its partial effectiveness. Since circumcised males are still required to use condoms, the intervention was seen as futile. The

speed and aggressive nature of the program fueled Swazi men's suspicions of Western health interventions leading to some questioning the origins of HIV/AIDS. This chapter also found that younger males were more likely to get circumcised compared to their older counterparts. This was further investigated in chapter 4.

The second chapter investigated men's perceptions of Test and Start. The first step in this initiative is to diagnose clients using an HIV test before linking them to care and treatment. Due to high HIV prevalence in the country, participants feared being diagnosed with HIV despite acknowledging the efficacy of modern HIV treatment. Most Swazis have had a friend or relative who has died from an HIV/AIDS related illness and this makes the disease an exceptional one. Many participants also stated that there is no hospitality in public health facilities and this is where they were supposed to get HIV treatment. They argued that these health facilities were not designed for everyone, especially men, and that long queues were also a major factor in keeping them away. The long queues and designated rooms for HIV treatment were also perceived as a barrier because it could expose their HIV status to other people who they may know. Nurses were also seen as unfriendly and potentially emasculating men. Some participants were also deeply concerned about the long-term consequences of starting ART while still healthy. They raised concerns about side effects, potential damage to vital organs such as the liver, and drug resistance overtime. Lastly, there were also concerns about the financial capacity of the Swazi government to be able to afford to buy HIV drugs in the future. This was based on the frequent drug stockouts widely reported in the country.

The fourth chapter investigated the social complexities of informed consent and assent among adolescent males undergoing circumcision. As stated above, older males were more resistant to circumcision compared to younger males. When implementers failed to reach targets while chasing older males, they turned their attention to younger, and easier to convince males.

This raised questions about informed consent and assent. The Eswatini VMMC program conforms to global standards, requiring that informed consent and assent be obtained before surgery. This chapter investigated how ethical guidelines were enacted in everyday practice in a setting where family dynamics and norms relating to autonomy and consensus make obtaining informed consent complex. The use of incentives, usually in the form of sporting goods was also seen as a threat to the adolescents' autonomy. Those promoting circumcision also focused on the benefits of getting circumcised and potential risks were relegated to a footnote. The chapter also discussed that parental authority overpowers young males' preferences regarding the decision to circumcise. The chapter concluded by arguing that consent process in practice is challenged by complex social, economic and political realities.

The last empirical chapter used masculinities as a lens into the continued poor uptake of circumcision services 10 years after the government of the Kingdom of Eswatini had signed the circumcision policy. The focus of the study was largely on sexuality, masculinity and the circumcision program in Eswatini. This chapter utilized critical discourse analysis and identified two discourses: sexuality, masculinity and circumcision, and income, masculinity, and circumcision. Similar to chapter two, the first discourse was linked to sexual performance and the threat from circumcision to hamper this critical marker of manhood. The second discourse highlighted the expectations from society that men as bread winners should always be capable of feeding their families. Loss of income during the recovery period post circumcision was a major barrier to some men, especially those doing manual labour.

The final chapter discusses the main findings and consolidates the main contributions of this study to existing literature in the field and ongoing discussions. Masculinities were central in this thesis and the conclusion further examines and discusses the concept of hegemonic masculinities, with a particular focus on local masculinities. The chapter concludes by recommending a multi-disciplinary team to tackle complex issues such as implementing

biomedical interventions in societies, to counter perspective blindness. The argument is that complex social issues usually cannot be solved by one person or profession, but requires a diverse set of skills and experiences to overcome each other's blind spots.

SAMENVATTING

Evidence-based medicine (EBM), en dan in het bijzonder effectieve biomedische technologieën die zijn ontdekt via gerandomiseerde gecontroleerde onderzoeken (RCT's), zijn zeer krachtige hulpmiddelen gebleken bij het vormgeven van de wereldwijde gezondheidszorg. Ondanks het bestaan van deze hulpmiddelen, de beschikbare subsidies voor implementatie daarvan en de politieke druk die deze subsidiegevers uitoefenen op regeringen in het zuiden van de wereld, hangt de acceptatie van deze krachtige medische technologieën af van hoe er naar deze technologieën wordt gekeken door de beoogde gebruikers. Dit is een complexe sociale kwestie die niet simpelweg kan worden opgelost door deze technologieën beschikbaar te maken.

Na drie baanbrekende RCT's in Zuid-Afrika, Oeganda en Kenia, waaruit bleek dat vrijwillige medische besnijdenis bij mannen (VMMC) de overdracht van hiv van vrouwen op mannen tot 60% kan verminderen, concludeerde de Wereldgezondheidsorganisatie (WHO) dat dit als afdoende bewijs gold en adviseerde de implementatie van VMMC in 14 voorkeurslanden, waaronder Eswatini. Al snel volgden subsidies en werden concrete doelen en beleidsagendas opgesteld. Het plan was om 80% van de mannen te besnijden in deze 14 landen in Sub-Sahara Afrika die een hoge hiv-prevalentie, en een lage percentage van besneden mannen kenden, zoals Eswatini. Een paar jaar later werd een nieuwe wetenschappelijke doorbraak aangekondigd: via een RCT werd aangetoond dat hiv-medicatie de overdracht van hiv tot 96% kan verminderden. Dit leidde tot de start van een hiv-interventie die later bekend zou worden als Test en Start, wat betekent dat alle mensen met de diagnose hiv zo snel mogelijk met hiv-remmers kunnen beginnen onafhankelijk van hun aantal CD4-cellen. Evereenkomstig aan de VMMC-aanbeveling van de WHO, introduceerde de Eswatini-regering ook Test and Start en waren Swazi-mannen één van de belangrijkste geselecteerde doelgroepen.

Op basis van etnografisch veldwerk is er in dit proefschrift onderzocht wat de percepties zijn van mannen uit Eswatini met betrekking tot VMMC en Test and Start. Ik wilde een *emic* perspectief krijgen op waarom er weinig gebruik werd gemaakt van deze gemakkelijk beschikbare en effectieve biomedische technologieën door Swazi-mannen. Dit proefschrift is gebaseerd op vier empirische hoofdstukken (hoofdstuk 2-5) die als afzonderlijke artikelen zijn gepubliceerd. In het eerste hoofdstuk zijn de doelstellingen en onderzoeksvragen van het proefschrift uiteengezet. Vanwege de focus van dit proefschrift op mannen is er uitgegaan van het concept van mannelijkheid als fundamenteel analytisch kader. Andere belangrijke concepten zoals *government experimentality* werden besproken in de inleiding en het hoofdstuk waarschuwt ook voor het her-medicalisatie van de hiv-respons. Dit hoofdstuk bracht ook een punt van zorg naar voren over het verdoezelen van de werkzaamheid en effectiviteit van biomedische interventies. In het geval van VMMC, en met financiering van de Amerikaanse regering, probeerde men in Eswatini de effectiviteit van VMMC in de realiteit aan te tonen door 80% van de Swazi-mannen in één jaar te besnijden. Eswatini bood de ideale eigenschappen voor dit experiment vanwege de kleine bevolkings -en geografische omvang, de hoogste hiv-prevalentie in de hele wereld en de relatief goed ontwikkelde infrastructuur. De noodzaak om een meerderheid van de Swazi-mannen te besnijden, middels de beschikbare subsidies, werd gelegitimeerd om daar zoveel mogelijk levens mee te redden in de kortst mogelijke tijd. Kortom, Eswatini was de uitgelezen locatie om VMMC-bewijs in een reële setting te verkrijgen door middel van deze interventies. Hoewel de aanbodzijde goed uitgerust en georganiseerd was, bleek er zeer weinig vraag naar de interventies te zijn.

In het tweede hoofdstuk werden de reacties en perceptie van mannen op VMMC onderzocht. Het was duidelijk dat oudere Swazi-mannen niet wilden zwichten voor de externe druk om hun voorhuid te laten verwijderen. Het besnijdenisprogramma stuitte op wijdverbreide weerstand van Swazi-mannen en middels etnografisch onderzoek heb ik informatie verzamelt omtrent deze weerstand. Een van de belangrijkste factoren voor de weerstand waren de

angsten en zorgen van mannen dat seks nooit meer hetzelfde zou zijn na de besnijdenis. Mannen waren bang dat het verwijderen van de voorhuid gevoelige delen zou verwijderen, de eikel zou verharden en daardoor zou leiden tot verminderde gevoeligheid van de penis. Dit werd verergerd door de angst voor bijwerkingen tijdens en na de besnijdenis. Het optreden van bijwerkingen zijn altijd een mogelijkheid bij operaties en bij besnijdenis speelt ook nog dat het een orgaan betreft dat voor veel Swazi-mannen centraal staat in hun mannelijkheid. Dus dit voelde voor hen als een bedreiging van hun mannelijkheid. Andere factoren die de acceptatie van besnijdenis bemoeilijken, was de gedeeltelijke effectiviteit ervan. Omdat besneden mannen nog steeds condooms moeten gebruiken, werd de interventie als zinloos beschouwd. De snelheid en het agressieve karakter van het programma wakkerden wantrouwen van Swazi mannen aan jegens Westerse gezondheidsinterventies, wat ertoe leidde dat sommigen de oorsprong van hiv/hivaids in vraag stelden. Dit hoofdstuk ontdekte ook dat jongere mannen zich eerder lieten leiden tot besnijdenis dan hun oudere landgenoten. Dit wordtverder uitgezocht in hoofdstuk 4.

Het derde hoofdstuk onderzocht de perceptie van mannen over Test en Start. De eerste stap in dit initiatief is het diagnosticeren van cliënten met behulp van een hiv-test voordat ze worden gekoppeld aan zorg en behandeling. Vanwege de hoge hiv-prevalentie in het land waren de deelnemers bang om de diagnose hiv te krijgen, ondanks de erkenning van de doeltreffendheid van moderne hiv-medicatie. De meeste Swazi's hebben wel een vriend of familielid die is overleden aan een hiv/aids-gerelateerde ziekte en dit maakt de ziekte uitzonderlijk. Veel deelnemers verklaarden ook dat zij niet welkom waren in de openbare gezondheidsinstellingen waar ze een hiv-behandeling zouden krijgen. Ze vertelden dat deze gezondheidsfaciliteiten niet voor iedereen waren ontworpen, en dan vooral niet voor mannen, en dat lange wachtrijen ook een belangrijke factor waren om weg te blijven. De lange wachtrijen en aangewezen behandelkamers voor de hiv-behandeling werden ook als een barrière ervaren omdat dit betekende dat hun hiv-status bekend zou kunnen worden bij andere

mensen die ze kenden. Verpleegkundigen werden ook gezien als onvriendelijk en mogelijk manonvriendelijk. Sommige deelnemers maakten zich ook grote zorgen over de langetermijngevolgen van het starten van hiv-remmers terwijl ze nog gezond waren. Daarnaast uitten ze hun bezorgdheid over bijwerkingen, mogelijke schade aan vitale organen zoals de lever en resistentie voor geneesmiddelen. Tot slot waren er ook zorgen over de financiële draagkracht van de Swazi-regering om in de toekomst hiv-medicijnen te kunnen kopen. Dit was gebaseerd op de frequente berichten in Swaziland over medicijntekorten.

Het vierde hoofdstuk onderzocht de sociale complexiteit van *informed consent and assent* (toestemming en instemming) bij adolescente mannen die een besnijdenis ondergaan. Zoals hierboven vermeld, waren oudere mannen minder geneigd om een besnijdenis te laten doen in vergelijking met jongere mannen. Toen de uitvoerders van het VVMC programma er niet in slaagden hun doelen te bereiken wat betreft benijdenis bij oudere mannen richtten ze hun aandacht op jongere en gemakkelijker te overtuigen mannen. Dit riep vragen op over de *informed consent and assent* methode, terwijl het VMMC-programma in Eswatini voldoet aan de wereldwijde ethische normen die vereisen dat geïnformeerde toestemming en instemming worden verkregen vóór de operatie. In dit hoofdstuk is onderzocht hoe de ethische richtlijnen in de dagelijkse praktijk tot stand werden gebracht in een omgeving waarin ook gezinsdynamiek en normen met betrekking tot autonomie en consensus het verkrijgen van geïnformeerde toestemming complex maken. Het gebruik van promotie goederen, meestal in de vorm van sportartikelen, werd ook gezien als een bedreiging van de autonomie van deze jongeren. De personen die besnijdenis promootten concentreerden zich vooral op de voordelen van besnijdenis en potentiële risico's werden daarbij naar de achtergrond geschoven. Het hoofdstuk besprak ook dat de opstelling van de ouders omtrent de beslissing tot besnijdenis over te gaan die van hun jonge zonen overheerst. Het hoofdstuk besloot met de stelling dat het toestemmingsproces in de praktijk wordt bemoeilijkt door complexe sociale, economische en politieke realiteiten.

Het laatste empirische hoofdstuk gebruikte het concept van mannelijkheid als uitgangspunt voor de aanhoudende slechte implementatie van besnijdenisdiensten 10 jaar nadat de regering van het koninkrijk Eswatini het besnijdenisbeleid heeft ondertekend. De focus van het onderzoek lag grotendeels op seksualiteit, mannelijkheid en het besnijdenisprogramma in Eswatini. Dit hoofdstuk maakte gebruik van kritische discoursanalyse en identificeerde twee discoursen: seksualiteit, mannelijkheid en besnijdenis, en inkomen, mannelijkheid en besnijdenis. Net als in hoofdstuk twee, was het eerste discours gekoppeld aan seksuele prestaties en de angst dat besnijdenis deze kritieke exponennt van mannelijkheid zou bedreigen. Het tweede discours benadrukte de verwachtingen van de samenleving dat mannen als broodwinnaars altijd in staat moeten zijn om hun gezin te voeden. Inkomensverlies tijdens de herstelperiode na de besnijdenis was een grote barrière voor sommige mannen, vooral degenen die handenarbeid verrichtten.

Het laatste hoofdstuk bespreekt de belangrijkste bevindingen en bevestigt de belangrijkste bijdragen van dit onderzoek aan de bestaande literatuur in het veld en de actuele discussies. Masculiniteiten stonden centraal in dit proefschrift en de conclusie onderzoekt en bespreekt het concept van hegemonische mannelijkheid verder, met een bijzondere focus op lokale mannelijkheid. Het hoofdstuk besluit met het aanbevelen van een multidisciplinair team om complexe problemen aan te pakken, zoals het implementeren van biomedische interventies in de samenlevingen, om perspectiefblindheid tegen te gaan. Het argument is dat complexe maatschappelijke vraagstukken meestal niet door één persoon of beroep kunnen worden opgelost, maar een diverse set aan vaardigheden en ervaringen vereisen om elkaars blinde vlekken te overwinnen.

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