Behavioural economics: The missing ingredient that makes sexual health services responsive and acceptable to young South Africans

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Declaration page

I, Philip Smith, hereby declare that all the work on this thesis is based on my original work and that neither the whole work or any part of it has been, or is being, submitted for another degree in this or any other university. In the case of multi-authored published papers, this constitutes work for which I was the lead author. My contribution to multi-authored papers is outlined in the preface of the thesis.

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Preface

This thesis contains four published papers which were adapted for use as chapters, as per general provision 6.7 in the General Rules for the Degree of Doctor of Philosophy (PhD) of the University of Cape Town. The role of each author is listed under the title. My supervisor was Linda-Gail Bekker, Professor of Medicine, in the Department of Medicine, University of Cape Town.

I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board to include the following publication(s) in my PhD thesis, and where co-authorships are involved, my co-authors have agreed that I may include the publication(s):

1. **Chapter two adapted from: Smith P., Marcus R., Bennie T., Nkala B., Nchabeleng M., Latka M.H., Gray G., Wallace M., Bekker L.-G. (2018). What do South African adolescents want in a sexual health service? Evidence from the South African Studies on HIV in Adolescents (SASHA) project. South African Medical Journal, 108(8), 677–681.**
   Philip Smith was lead author, conceptualised and conducted the data analysis.
   Rebecca Marcus collaborated in discussions around data analysis, data interpretation, and critically reviewed the manuscript.
   Thola Bennie was a co-investigator who was involved in study design, supported data collection, and reviewed the manuscript.
   Busi Nkala was a co-investigator who was involved in study design, supported data collection, and reviewed the manuscript.
   Maposhane Nchabeleng was a co-investigator who was involved in study design, supported data collection, and reviewed the manuscript.
   Mary Latka was a co-investigator who was involved in study design, supported data collection, and reviewed the manuscript.
   Glenda Gray was co-investigator who was involved in study design, supported data collection, and reviewed the manuscript.
   Melissa Wallace was project coordinator, conceptualised the study, supervised the study, the data analysis, and critically reviewed the manuscript.
   Linda-Gail Bekker was project lead investigator, conceptualised the study, and critically reviewed the manuscript.

2. **Chapter three adapted from: Smith, Philip, Tolla, T., Marcus, R., & Bekker, L.-G. (2019). Mobile sexual health services for adolescents: Investigating the acceptability of youth-directed mobile clinic services in Cape Town, South Africa. BMC Health Services Research, 19(1), 584.**
   Philip Smith was lead investigator, lead author, conceptualised the study, designed the data analysis, conducted the study, cleaned and merged all data, and conducted the data analysis.
   Tsidiso Tolla supported data collection, collated the data, and reviewed the manuscript.
   Rebecca Marcus collaborated in data analysis and critically reviewed the manuscript.

Linda-Gail Bekker was coinvestigator, oversaw study design, and critically reviewed the manuscript.

3. **Chapter four adapted from: Smith, P., Wallace, M., & Bekker, L.-G. (2016). Adolescents' experience of a rapid HIV self-testing device in youth-friendly clinic settings in Cape Town South Africa: A cross-sectional community based usability study. Journal of the International AIDS Society, 19(1).**
   Philip Smith was lead investigator, lead author, conceptualised the study, designed the data analysis, conducted the study, cleaned and merged all data, and conducted the data analysis.Melissa Wallace supervised the study design, implementation and data analysis, and critically reviewed the manuscript.
   Linda-Gail Bekker was coinvestigator, oversaw study design, and critically reviewed the manuscript.

4. **Chapter five adapted from: Smith P., Oulo B., Wallace M., Gill K., Beijneveld N., Bennie T., Myer L., Dietrich J., Gray G., Bekker L.-G. (2019). Young male's uptake and acceptability of Medical Male Circumcision in two culturally distinct settings in South Africa: A longitudinal, community-based study: The MACHO Study. SAMJ: South African Medical Journal.**
   Philip Smith was a coinvestigator and lead author. He helped design the study, and helped design the data analysis, cleaned and merged all data, conducted the data analysis.
   Brenda Oulo assisted with data analysis and reviewed the manuscript.
   Melissa Wallace was the project director, conceptualised the study, supervised the study and data analysis, and critically reviewed the manuscript.
   Katherine Gill was a co-investigator who was involved in study design, managed data collection, and reviewed the manuscript.
   Nathan Beijneveld assisted with data analysis, and reviewed the manuscript.
   Thola Bennie was involved in study design and supported data collection.
   Landon Myer was a co-investigator, helped with study design and reviewed the manuscript.
   Janan Dietrich managed data collection and data analysis and reviewed the manuscript.
   Glenda Gray was site lead investigator and reviewed the manuscript.
   Linda-Gail Bekker was lead investigator, conceptualised the study, and critically reviewed the manuscript.

The candidate drafted all versions of each manuscript and was the lead and corresponding author on all the included papers. All co-authors critically reviewed and approved the submitted manuscripts. The senior author on each paper has confirmed to the University of Cape Town Doctoral Degrees Board that the included papers reflect the candidate's independent scientific work.

Signature: **Date:** 2019/02/07

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Abstract

Introduction: South African adolescents and young adults (AYA) remain at high risk of HIV infection despite reductions in HIV incidence in older adult populations. This is, in part, attributable to suboptimal levels of health-seeking behaviour. Behavioural economics provides insight into why conventional efforts to generate health-seeking behaviour have struggled to curb HIV infection in South African AYA and in designing more desirable, scalable interventions to better serve youth and promote sexual health.

Methods: Focus group discussions gathered information on sexual health service wants from AYA in high HIV disease burden, limited resource communities. Based on this data, three AYA friendly services were designed, including a diagnostic screen (HIV self-testing, HIVST), a prevention intervention (male medical circumcision), and a service platform (mobile clinic). All three studies evaluated acceptability. The circumcision and the mobile clinic studies described service uptake. The mobile clinic study compared uptake of services with four conventional clinics in the same community.

Results: Participants recommended that services be easily accessible, friendly services, age appropriate, tailored information, and improved relationships with healthcare workers. Participants in the mobile clinic study (n=304) rated mobile services' acceptability highly (median = 4,6 out of 5), attracting more males proportionally than conventional clinics. The HIVST study (n=224) found high fidelity (96%), usability (median 3.9 out of 5), and acceptability ratings (median 4.3 out of 5). The circumcision study conducted in culturally distinct locations (Cape Town n=50; Soweto n=50) identified that Soweto males in this age range (14-17 years) were 19 times more likely (n=13) to have been circumcised than those in Cape Town (n=1) (HR 18.9, 95% CI 2.37-150.71, p= 0.006) over study duration.

Conclusions: Given the high ratings for acceptability, AYA tailored services should be investigated as part of a multipronged approach to diagnostic, prevention, and health system options. Besides development and age considerations, the contrast between MMC uptake in Cape Town versus Soweto indicate that cultural beliefs and tradition may also strongly influence specific key interventions. Overall, using a behavioural economics framework to design and implement AYA recommendations received a positive reception. These findings support recommendations to provide differentiated care to AYA.

345 words

Contents

Table of tables, figures, and pictures

Prologue

South African adolescents and young adults continue to experience high rates of HIV-related morbidity and mortality specifically associated with sexual risk behaviour. Despite numerous efforts to adapt healthcare services to adolescents and young adults, both research and implementation have had limited impact upon shepherding them into healthcare to facilitate the reduction of sexual risk and the associated unintended outcomes. Redirecting suboptimal usage of services requires innovative ideas that can increase health-seeking in young people, including the adoption of prevention or treatment strategies, with improvement of their outcomes and quality of life. The behavioural economics model has had success in solving a range of perplexing problems in the fields of economics, education, and public health. Specifically, health researchers and policy makers have used behavioural economics to improve health outcomes, both within and outside of the field of HIV. However, while cash incentives are popular in sexual health research, novel aspects of behavioural economics have yet to be tested to improve health-seeking behaviours for HIV and sexual health services. This research sought to better understand why young people continue to elude and eschew sexual health services and what qualities they would desire in health services. The research also explored new approaches to adolescent health-seeking behaviour, through a behavioural economics lens.

Chapter one: Introduction

This thesis aims to investigate adolescent appropriate models of care that improve accessibility and uptake of sexual and reproductive health, HIV prevention, and treatment services among adolescents and young adults, using an innovative behavioural economics approach.

Problem statement: South African adolescents and young adults remain at high risk of HIV infection

Young South Africans (15-24 years) remain at high risk of HIV infection despite decades of sustained and costly interventions to improve HIV awareness and to encourage HIV testing, and subsequent treatment or prevention initiation. Interventions have not optimally generated health-seeking in young people in part due to overreliance upon rationality-based behaviour modification (Figure 1: system 2) (Kahneman, 2011; Thaler & Sunstein, 2008) models in a context with multiple personal and structural barriers to accessing sexual and reproductive health services (SHS). Given the adolescent stage in neurodevelopment, it may actually be recommended that interventions should use intuitive behavioural models (system 1) that improve convenience and reduce barriers to the uptake of SHS. This thesis will present evidence that designing SHS based on behavioural economics models will improve the convenience and desirability of services.

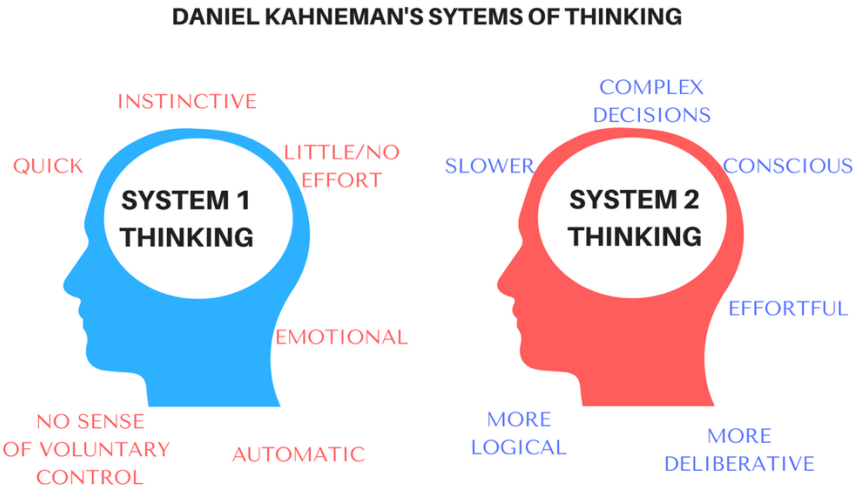


Figure 1: Two systems of behaviour modification (system 1 is fast, system 2 is slow).

(https://medium.com/the-mission/how-to-increase-your-brain-power-and-improve-the-quality-of-outputs-you-produce-9d4171ad2899)

The biological and psycho-social transitions during adolescence and young adulthood are commonly accompanied by the initiation of sexual intercourse, and consequently, the need for SHS (Bekker, Johnson, Wallace, & Hosek, 2015). South African SHS have not optimally served adolescents and young adults (AYA), which in part has resulted in suboptimal adoption of HIV testing, prevention, and treatment (Denison et al., 2017; Strauss, Rhodes, & George, 2015). To illustrate, while 85% of South Africans who were HIV positive had tested and knew their HIV status, this figure was 24% in males and 65% in females 15-24 years (HSRC, 2018). Moreover, modelling suggests that 36% of all heterosexual transmission of HIV occurs in the 15-24 age group (Johnson, Dorrington, Bradshaw, Pillay-Van Wyk, & Rehle, 2009). Messaging campaigns have traditionally been pathogenic, medically framed information around risk (Pettifor, Stoner, Pike, & Bekker, 2018). Adolescents, being generally well, find it difficult to identify with risk-centred messaging and tend towards salutogenic, wellness centred messages (Antonovsky, 1996).

Salutogenic approaches to health contrast, yet compliment pathogenic (disease-focused) approaches to healthcare (Antonovsky, 1993, 1996). Pathogenic approaches focus on curative healthcare, treating illness, or illness centred care. Salutogenesis is the *generation and maintenance* of healing, recovery, repair and wellness. Salutogenic approaches to healthcare focus particularly on the relationship between health, stress and coping and map pathways for social institutions to ensure that, "…risk factors which can be reduced or done away with at the level of social action are handled, and that social conditions allow, facilitate and encourage individuals to engage in wise, low risk behaviour" (Antonovsky, 1996, p 13). Antonovsky developed the salutogenic approach in the hope that researchers would identify practicable pathways that create and maintain health. As such, salutogenic approaches focus on health generation and maintenance, while pathogenic approaches focus on disease processes. Antonovsky emphasized that both pathogenic and salutogenic processes are important and should run parallel in our understanding of health and disease.

Interventions have relied too heavily upon adolescents' auto-generated health-seeking behaviour (Patton et al., 2016). Additionally, competing priorities and real and perceived contextual, structural, social and personal barriers within limited-resource areas in South Africa have inhibited health behaviour in communities where the burden of HIV infection is highest (Strauss et al., 2015). This has all subsequently contributed to high HIV-related mortality in AYA compared with older adult populations.

Traditional models of behaviour modification largely use rational, step-wise processes (system 2) to explain behaviour modification and develop interventions (Hardcastle et al., 2015). These models suggest that if individuals are exposed to the right information, they will act rationally to maximise the

goal of personal benefit and reduce unwanted outcomes. While traditional models are useful at describing conscious decision-making processes and resultant behaviour, they are insufficient because much of human behaviour is conditioned and generated automatically in response to environmental cues. The science of decision making (Kahneman, 2011; Thaler & Sunstein, 2008) can help understand why efforts to generate health-seeking and curb HIV infection have been largely ineffective in South African AYA (Krishnan et al., 2008; Zuma et al., 2016). These new ways of thinking can, simultaneously, assist in architecting more desirable, intuitive and potentially scalable interventions to better serve young people.

In behavioural economics, architecting additional options to increase a behavioural outcome is termed 'libertarian paternalism' because healthy options are provided and encouraged while less healthy options are not restricted. "Libertarian paternalism is a relatively weak, soft, and non-intrusive paternalism, because choices are not blocked, fenced off, or significantly burdened" (Thaler & Sunstein, 2008, p. 5). Essentially, even though we are attempting to influence (paternalism) healthy behaviour through deliberately providing choices (choice architecture), people should remain free to choose (libertarian), which is something young people want to begin doing as part of their natural development towards independent adulthood (Blakemore, 2018; Blakemore & Robbins, 2012). Traditional behavioural theories accept that people are rational, and that goal-directed behaviour is generated based on information aimed at maximising personal utility (Taylor et al., 2006), or in other words, people act to maximise their personal benefit. But when there are competing priorities, people very often choose to behave in seemingly irrational ways that clearly thwart personal utility. For instance, Dan Ariely (2009), a behavioural economist, has described numerous situations where people make predictably irrational decisions. One example of predictably irrational behaviour includes thinking and experiencing that more expensive aspirin is more likely to cure a headache, even when both the expensive and cheap pill were both vitamin C. This experiment seems to indicate that we have greater belief in more expensive cures. Another example of predictable irrationality is that cigarette warnings counterintuitively increase cigarette purchases because we seek to minimise the anxiety and sense of vulnerability associated with personal risk by engaging in the risky behaviour (Arndt et al., 2013; Millar & Millar, 1995). These lapses in rationality abound and present problems for public healthcare.

Although people often know that early diagnosis can prevent illness and death, many people choose to delay health-seeking behaviour (Cooper, Goldenberg, & Arndt, 2011), such as HIV testing. Knowing that HIV eradication is the aim, but that people evidently delay health-seeking, how do we influence better decisions which lead to healthier behaviour and healthier outcomes? HIV interventions that

require behavioural uptake should necessarily use choice architecture to influence behaviour, which entails a degree of paternalism.

Thaler and Sunstein (2008) argue that three erroneous beliefs about paternalism lead to ineffective strategies for increasing health-seeking. The three underlying beliefs include, 1) the notion that paternalism is bad because it is coercive, 2) the belief that paternalism can be avoided, and 3) the belief that people can arrive at personally beneficial outcomes on their own without the assistance of paternalism. Thaler and Sunstein challenge these beliefs and argue that, while traditional paternalism *is* coercive, it is unethical not to provide options that influence behaviour in predictable ways, often termed a nudge, to assist people with making decisions that maximise both personal and public health benefit. A nudge is not a directive and should be easy to reject. Libertarian paternalism, as opposed to coercion, presents personally valued options that make health-seeking and healthy outcomes more likely. Before these options can be made available, it is important to understand the problems that reduce health-seeking. These problems include personal, social and structural barriers that prevent health-seeking behaviour. Based within the behavioural economics theoretical framework, four studies were developed for this thesis to investigate what South African AYA want in differentiated SHS to optimally serve AYA and to improve sexual and reproductive health-seeking behaviour.

Research aims: To investigate and implement what adolescents want in sexual health services

The first aim of this thesis was to explore what adolescents want in a SHS. The second aim was to use the behavioural economics framework to design, pilot and investigate the acceptability and uptake of AYA friendly services that incorporated adolescent recommendations. This was done in three defined areas of public health engagement; 1) a health system delivery platform, 2) diagnosis and screening, and 3) prevention intervention. The empirical research firstly included qualitative focus group discussions with adolescents from five research sites across South Africa which sought to understand barriers and facilitators to accessing SHS. Secondly, based on the data from the focus groups, three interventions were designed and piloted with the aim of investigating the acceptability of services tailored for adolescents. The research objectives of this thesis were to investigate through mixed methods and implementation research, a health system platform, a diagnostic tool, and prevention for AYA; specifically,

1. To investigate what AYA want in sexual health services
2. To design and implement AYA recommendations for an:
    a. HIV diagnostic service
    b. HIV prevention service
    c. SHS delivery platform
3. To investigate the acceptability of the three interventions

The South African context: The impact of HIV in adolescents and young adults

Sexual debut occurs around middle adolescence (16.5 years) (Simbayi, Chauveau, & Shisana, 2004; Zuma et al., 2010). Additionally, HIV infection spikes between late adolescence and early adulthood in South Africa (Shisana et al., 2014), and HIV-related deaths have increased in this age group while decreasing in paediatric and older adult populations (Denison et al., 2017). While the HSRC (2018) report estimated the national HIV prevalence at 14% in South Africa, this rate increased rapidly from around 5% in both males females 15-19 years to 15,6% in females 20-24 years with no change in males prevalence. The increase in prevalence suggests that this period of development presents an opportunity for diagnostic, prevention and treatment interventions. Specifically, worldwide there were approximately 250,000 new HIV infections annually in adolescents (Chandra-Mouli, Armstrong, Amin, & Ferguson, 2015) with an estimated 139,000 in South Africa (Shisana et al., 2014). Additionally, 65% of those infections in youth aged 19-24 years and modelling suggests over a third (37%) of HIV infections occur through heterosexual transmission (Johnson, Dorrington, Bradshaw, Pillay-Van Wyk, & Rehle, 2009). While 85% of adult South Africans living with HIV knew their status, this figure was only 25 those 15-24 years (HSRC, 2018). AYA living with HIV were less likely to be on treatment (39,9%) than the overall population (62,3%). Viral load suppression in AYA (48%) was lower than in older adults (62.3%).

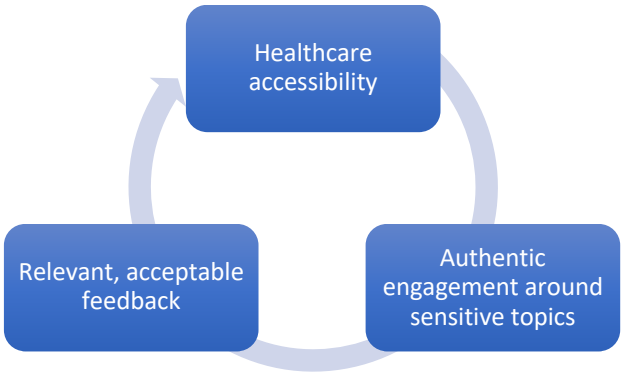
While knowledge of HIV transmission and prevention varies, many young people have not adequately protected themselves (S James, Reddy, Taylor, & Jinabhai, 2004). A systematic review found that this outcome was common in the sub-Saharan region (Zgambo, Kalembo, & Mbakaya, 2018). Even though a lack of comprehensive knowledge is associated with lower protective behavioural intentions, young people especially frequently delay health-seeking behaviour which is in their best interest, (Meyer-Weitz, Reddy, Van Den Borne, Kok, & Pietersen, 2000; Rice, 2013). Many South African AYA do not engage with healthcare until they are ill and symptomatic and in need of complex interventions, which results in late diagnosis and prolonged opportunities for transmission (van Schaik, Kranzer, Wood, & Bekker, 2010).

Though HIV testing has increasingly become the gateway to non-communicable disease detection, prevention, treatment and care (Black et al., 2014; Youngs & Hooper, 2015), the current context in South Africa, however, presents barriers to facilitating early healthcare intervention and wellness, especially for young people (Delany-Moretlwe et al., 2015; Hosek et al., 2016; Strauss et al., 2015; Wood & Jewkes, 2006). Mayosi and Benatar (2014) recommended that significant scale-up of health services could strengthen the healthcare system to implement primary and secondary interventions that meet the healthcare needs of South Africans. Even so, these recommendations are longer-term and costly.

Many young people delay health-seeking and do not access conventional healthcare services because visits can be a hassle (Chang, Webb, & Benn, 2017; Thaler & Sunstein, 2008). The 'hassle factor' is an enormous barrier for young people. Contrary to the idea that young people have an invulnerability complex and do not want to access healthcare (Reyna & Farley, 2006; Strauss et al., 2015), there are competing priorities and significant structural and personal barriers which make visiting healthcare complex, time-consuming and unpleasant, and so worth putting off (Strauss et al., 2015; Wood & Jewkes, 2006).

Research in the South African context has shown that both youth who believed themselves to be at risk of HIV infection due to unsafe sexual encounters anticipating a positive result, and those not currently sexually active, were less likely to seek out an HIV test (Strauss et al., 2015). It is problematic that the former group, those most at risk and in need of SHS, do not seek out healthcare. Ataguba and McIntyre (2013) proposed that more and improved services were needed to address delayed health-seeking, particularly in lower socio-economic communities with the highest burden of disease and where access and benefit were most lacking. Separate studies have shown that there is a shortage of professional healthcare staff (Ameh et al., 2017; Mayosi & Benatar, 2014), and Mayosi and Benetar (2014) suggested that South Africa needed three times the healthcare workforce to adequately care for patients infected with HIV alone, where many of those who were newly infected were in the 15 – 24 year old age group (HSRC, 2018; MacPhail, Pettifor, Coates, & Rees, 2008). Understandably, tripling the size of the healthcare workforce and housing this workforce in facilities is an aspirational goal. Accordingly, addressing real and perceived personal, social and structural barriers to accessing healthcare services needs innovative strategies that implement early intervention, prevention, treatment and wellness for young people. Young people need practical solutions to overcome multiple complex barriers to health-seeking behaviour. At the very least, health-seeking needs to be more desirable if uptake and self-management is to increase.

Health services need to improve by bridging the gap between healthcare facilities and young people through providing more acceptable, differentiated models of care (Bearinger, Sieving, Ferguson, & Sharma, 2007; Bygrave, 2016; Grimsrud, Barnabas, Ehrenkranz, & Ford, 2017; Haberer et al., 2017; Sawyer et al., 2012; Sohn, Vreeman, & Judd, 2017). Traditionally, differentiated models of care have been used to mould antiretroviral treatment (ART) delivery with the intent of managing HIV patients outside of conventional care settings (Grimsrud et al., 2017). However, differentiated models of care could be extended to the entire care cascade, from case detection, to linkage-to-care, prevention and



treatment initiation, regimen adherence, viral suppression for those HIV positive, and HIV prevention for those HIV negative. Differentiated options include active case-finding and decentralised and community-based models which enable early health-seeking, earlier diagnoses, preventing illness and symptoms, and which reduce healthcare cost on managing complex co-morbidities, especially for populations such as men and adolescents who are prone to avoid conventional health services (Bassett et al., 2014, 2013; Black et al., 2014; Sharma, Barnabas, & Celum, 2017; Smith et al., 2015). This thesis investigated a more desirable, differentiated, salutogenic model of AYA friendly healthcare:

1. that young people deem physically and psychologically accessible (in limited-resource communities),
2. that young people deem acceptable, and even desirable,
3. that young people value and can engage with more honestly.

Barriers to the uptake of sexual health services: structural and personal

South Africa experiences high rates of chronic illness and has the highest number of HIV infections in the world (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Dalal et al., 2011; Mayosi et al., 2009). Moreover, life expectancy in South Africa dropped dramatically from 61 to 51 years between 1994 and 2005, largely as a result of the HIV epidemic and the rapid increase in AIDS-related deaths (Bor, Herbst, Newell, & Bärnighausen, 2013; Mayosi et al., 2012). In response to the HIV epidemic, large local and international resources were invested in educating South Africans about how to test and protect against HIV infection (Peltzer et al., 2012) and how to live healthily with HIV (Bärnighausen

et al., 2011). These efforts to encourage protection against infection through behavioural change had minimal effect on infection rates, evidenced by the continued increase of the infection rate until around 2003 (Hargreaves et al., 2007). The infection rate began to plateau around this time (Dickinson, 2009; Pettifor et al., 2005). There was also a plateau in prevalence, which seemed to be due to the number of AIDS-related deaths, largely as a consequence of the South African government withholding the rollout of ART for people with HIV (Chigwedere, Seage, Gruskin, Lee, & Essex, 2008; Dickinson, 2009; Gevisser, 2007; Nattrass, 2007). Many lives were unnecessarily lost between 2003 and 2008 due to the inadequate ART rollout. The change in the South African administration in 2008 changed course for the epidemic and saw the start of the biggest anti-retroviral treatment program.

ART rollout resulted in reductions of mother-to-child HIV transmission (Barron et al., 2013; Black et al., 2013), lower rates of HIV-related mortality for perinatally infected infants (Johnson et al., 2012) and the return to near normal life expectancy for HIV positive individuals on treatment (Johnson et al., 2013). In addition to the rollout of the ART program, there were a few more advances that curbed the HIV epidemic in South Africa. In the 2008 national survey, compared to the previous national surveys, more young people (15-24 years) reported ever having an HIV test, and the levels of condom use at last sex and over the course of being sexually active had increased (Rehle et al., 2010).

However, in 2014 Olive Shisana's Human Sciences Research Council report showed that the encouraging gains made in prevention in the first decade of the 2000s had been somewhat undone (Shisana et al., 2014). While HIV information reached most of the population, the number who reported using prophylactic measures to protect from infection had declined and the number of youth in age-disparate relationships had increased between 2008 and 2012. This was due to several factors, including cultural beliefs about the use of HIV protection and consequently, reported difficulties around negotiating the use of HIV protection (Maticka-Tyndale, 2012; Reddy & Frantz, 2011). In summary, the expensive education campaigns were remarkably slow at lowering and reversing the HIV infection rate (Ganz, Neville, & Ward, 2017). Finally, a strong focus on treatment may have removed focus and resources on prevention. Despite gains in treatment in other populations, we have not seen the same in AYA and young men (Bekker & Hosek, 2015).

There were several barriers responsible for the delayed uptake of HIV services. Accessing healthcare often entails long waits, multiple visits, multiple and fragmented facilities, unfriendly healthcare professionals, inaccurate or generic information, long commutes, unpaid breaks from employment, the constant barrage of mild to mortal threats of dreaded outcomes, and the ominous expectation that one may be ill with a chronic fatal disease (Strauss et al., 2015; Wood & Jewkes, 2006). The multiple developmental transitions during this period place AYA at increased risk of late diagnosis,

poorer prevention uptake, poor linkage-to-care, treatment, retention and adherence (Bekker, Johnson, Wallace, & Hosek, 2015; Hosek et al., 2016; Pettifor et al., 2013).

In addition to the personal, structural and social barriers listed above, systematic reviews of adolescent SHS have shown that the cultural, legal and political context can greatly influence access; the context can impair or improve access and uptake of prevention and treatment (Denno, Chandra-Mouli, & Osman, 2012; Hardee, Gay, Croce-Galis, & Afari-Dwamena, 2014; Hardee, Gay, Croce-Galis, & Peltz, 2014). These reviews have shown that, in addition to poverty alleviation, enabling legal, political, and cultural norms are crucial in promoting access to SHS and improving sexual health outcomes in adolescents.

Consequently, the impact of HIV has been worse in AYA: while HIV infection and HIV-related deaths had decreased in paediatric and older adult populations (Bor et al., 2013), there was worse virological suppression (Nglazi et al., 2012) and increased HIV mortality in AYA 15 – 24 years (Wood, Dowshen, & Lowenthal, 2015). In adolescence, the biological, psychosocial and neurodevelopmental changes are associated with increased risk-taking, leading to increased susceptibility to HIV infection, while increased independence is associated with increased treatment failure (Marcus, Ferrand, Kranzer, & Bekker, 2017; Victor & Hariri, 2016). Moreover, early HIV acquisition with later diagnosis and treatment has translated into greater potential to transmit HIV than those who are infected during later adulthood (Bekker et al., 2015). In youth, this period could be many years of potential transmission. The evidence of poorer outcomes in youth highlights the need for identifying the precursors of better outcomes in this age group.

It is concerning that the infection rate in young South Africans in 2019 is still amongst the highest in the world after the vast local and international investment to curb the epidemic. However, broadly, health communication around risk behaviours, such as alcohol abuse prevention, tends to have little effect upon persuading behaviour change (Alcohol and Public Policy Group, 2010). Similar effects are evident for HIV information communication. Based on their research with young adults, two researchers from the University of Cape Town, in South Africa, suggested that media education, instead of increasing health-seeking behaviour, had produced an information fatigue among young adults (Levine & Ross, 2002). The large educative efforts disseminating information had made participants weary, with one participant stating, “We are sick and tired of hearing about AIDS, AIDS, AIDS!” (Levine & Ross, 2002, p. 96).

Levine and Ross’s interviews with young adults suggested that the information fatigue young people had experienced had led to behavioural apathy. Instead of encouraging greater levels of health-

seeking and protective behaviour, the information seemed to have had the opposite effect, resulting in behavioural apathy in the face of risk! What makes South African young people, the most at risk demographic for HIV (Pettifor et al., 2005), exhibit behavioural apathy in the face of risk? More surprisingly, what makes young people continue to exhibit risk behaviour knowing that wasting and death are potential outcomes? To provide some answers to these questions, three different adolescent-friendly initiatives based on participatory youth research sought to provide adolescents and young adults with more appropriate SHS, and are presented here in this thesis.

Adolescent sexual healthcare services in South Africa

Although billions of dollars had been spent on HIV eradication in South Africa, the efforts and messaging had not had the desired effect of reducing HIV infections in AYA (Galárraga, Colchero, Wamai, & Bertozzi, 2009; Ganz et al., 2017; Krishnan et al., 2008). The messages focused on the importance of protecting oneself from infection and HIV testing to know one's HIV status. Testing, prevention and treatment options have been widely available and have the potential to prevent comorbidity and costly interventions for chronic HIV (Ganz et al., 2017; Mogler et al., 2013). While educating the public about the available health options is necessary and crucial (Antonovsky, 1993), it is evident that the mitigating effect of information on health behaviour is limited (Ölander & Thøgersen, 2014): education alone rarely increases prevention and protection behaviour.

When surveyed, young South Africans were generally aware of how to prevent HIV infection, but it was clear that being informed had little impact on reducing risky sexual practices (Cluver, Orkin, Yakubovich, & Sherr, 2016). Moreover, in 2012 condom use had decreased and age-disparate relationships had increased from levels previously surveyed in South African youth in 2008 (Zuma et al. 2016). Worryingly, at the height of the epidemic, young South Africans had reported increased risky behaviour. Increased risk behaviour in the face of known risk indicates that young people may have cognitively disengaged from perceiving their personal risk and disengaged from health-seeking and potentially protective behaviours. Young people may have cognitively disengaged from HIV to escape the negative emotion linked with contemplating personal risk of contracting HIV and the associated dread of wasting and death (Chang et al., 2017; McKirnan, Ostrow, & Hope, 1996; Millar & Millar, 1995). Ostensibly, thinking about one's personal risk of contracting a dread disease may elicit undesirable emotions, resulting in avoidance and limited effect on health-seeking behaviour.

While there have been efforts to address these barriers, such as training healthcare staff in adolescent-friendly care through projects such as NAFCI (National Adolescent Friendly Clinic Initiative), independent investigation revealed that implementation in government clinics was not in

line with policy, and therefore, not ideal (Dickson, Ashton, & Smith, 2007; Dickson-Tetteh, Pettifor, & Moleko, 2001; Geary, Gómez-Olivé, Kahn, Tollman, & Norris, 2014; Geary, Webb, Clarke, & Norris, 2015). To demonstrate, interviews conducted with adolescents who visited healthcare services indicated that experiences were discouraging because staff were unfriendly and judgemental, there was a lack of privacy, the visits were long and often required more than one visit if ill, with the additional dread of being diagnosed with a chronic condition (Geary et al., 2015) (Chapter two contains more in-depth discussion of NAFCI). If symptoms are not unbearable, the cost of visiting a primary healthcare facility may be experienced as dearer than waiting for the illness to resolve spontaneously. The immediate benefit of avoiding an unpleasant and likely unhelpful clinic interaction may be the preferable option, while accessing private healthcare is impossible because the financial cost places this option out of range of most young South Africans.

Considering these barriers can be understandably dispiriting, and it may seem preferable to delay a clinic visit until symptoms become uncomfortable and distress makes engagement unavoidable. By this time, however, patients often require complex interventions, which can be costly and require more time and expertise on the part of healthcare services. Knowing that young people experience these barriers, innovation is required to transform the current, expensive, time-consuming, fragmented and complicated healthcare services to be more desirable. Desirable healthcare might include the delivery of acceptable and practicable healthcare interventions that more efficiently diagnose, prevent and treat illness and generate long-term wellness.

The limited impact of mass education and training of the healthcare workforce to encourage health-seeking behaviour contributed partly to the protracted HIV epidemic in young people. This requires insight into how people think about their personal vulnerability and how these beliefs impact health-seeking behaviour. Evidently, young people display apathy and denial in the face of future threats (Joffé, 1999; Levine & Ross, 2002), a seemingly irrational response. Behavioural research offers that people behave irrationally because of a number of cognitive biases (Kahneman, 2011; Rice, 2013). While we enjoy anticipating desired and hoped-for future outcomes, it is difficult to think about disease vulnerability because it requires uncomfortable thoughts about the inevitability of death in general, and painful, wasting terminal disease in particular (Millar & Millar, 1995). Certainly, the evidence suggests that people who display optimistic bias and motivated reasoning to back personally edifying beliefs tend to be happier (Kunda, 1990). We would rather avoid contemplating our vulnerability and inevitable demise, and instead, focus on gratification. Avoidance and irrational thinking, however, rarely generate health-seeking behaviour.

Risk and rationality: Theoretical approaches to health behaviour change

Since behavioural factors heavily influence disease-related mortality, behavioural models have been used to explain health behaviour and to design interventions that encourage health-seeking to improve and maintain wellness, and prevent illness and death (Glanz & Bishop, 2010). Starting in the 1950s behavioural models have been developed to understand health behaviours in the contexts in which they occur. Consequently, public health interventions have implemented and tested these models and improved public health through evidence-based evaluation. Three of the most commonly used cognitive theoretical models are the health belief model (HBM) (Rosenstock, 1974), protection motivation theory (PMT) (Prentice-Dunn & Rogers, 1986) and social cognitive theory (SCT) (Bandura, 1977b).

Various theoretical models of health behaviour demonstrate how threat narrows adaptive behavioural responses (Fredrickson, 2004), engages vulnerability-denial defence mechanisms (Joffé, 1999; Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006; Pyszczynski, Greenberg, & Solomon, 1999), lowers health-seeking intentions and lowers health-seeking behaviour (Grover & Miller, 2014; McKinney, McSpirit, & Pomeroy, 2000; Millar & Millar, 1995), and can even have the opposite of the intended health-generating effect. PMT demonstrates that threat-based communication can facilitate healthy behavioural change and adaptive behaviours if these communications are paired with information about practical coping strategies (Prentice-Dunn, Mcmath, & Cramer, 2009; Prentice-Dunn & Rogers, 1986). Even so, threat-based communication has not had the intended effect to curb the impact of HIV in South Africa (Hargreaves et al., 2007; S James et al., 2004), as evidenced by the continued high HIV infection rate (Dickinson, 2009; Pettifor et al., 2005). Health interventions may have had limited impact because theoretical models of human health behaviour often posit that humans are rational thinkers who behave to maximise personal gain (utility) (Prentice-Dunn & Rogers, 1986; Reyna & Farley, 2006; Thaler & Sunstein, 2008). However, it is evident that humans often do not act rationally and that there are patterns to that irrationality.

Traditional health models

The following sections will briefly explore traditional, rationality-based models of behaviour change. The traditional theories are particularly useful at explaining deliberate decision-making and the resultant effortful behaviour, these models do not adequately account for non-rational behaviour. Accordingly, an understanding of adolescent neurological and psychological development is crucial in understanding adolescent behaviour motivation and will be explored briefly. Next, alternative models, including Terror Management Theory (TMT) (Cooper et al., 2011; Goldenberg & Arndt, 2008) and

Behavioural Economics (Kahneman, 2011; Thaler & Sunstein, 2008) will be explored, bridging the gap to contextualise the seemingly irrational human health behaviour. These alternative theories were developed to understand the systematic biases and errors in human decision-making and behaviour. These theories have also been used to design practical choices that nudge behaviour towards improved health outcomes.

The HBM is widely employed in designing interventions and to explain health behaviour uptake and avoidance, and while studies indicate prediction capability, reviews indicate relatively low prediction ability (Orji, Vassileva, & Mandryk, 2012). Overall, while PMT acknowledges that people do not always act rationally and that self-efficacy plays a significant role in health-seeking behaviour, cognitive theories of health behaviour generally express that health behaviour is the result of deliberate cognition leading to action.

Albert Bandura's SCT (formally social learning theory) (Bandura, 2001; Bandura & McClelland, 1977; Glanz & Bishop, 2010), based on the work of Kurt Lewin (Rosenstock, Strecher, & Becker, 1988), departed from the earlier mutually exclusive models; the psychodynamic model and behaviourist model of behaviour change. At the time, the psychodynamic model focused on the internal motivations of human behaviour, where the behaviourist model discounted internal cognitive causes and studied behavioural modification through environmental stimuli.

In SCT, reciprocal determinism is integral to understanding how cognition (thought, emotion and physiology), behaviour and environment dynamically influence behaviour change. A review of systematic reviews of behavioural modification found that self-efficacy (one of the tenets of SCT) has been consistently associated with behaviour change (Bauman et al., 2012). Specifically, a review of sub-Saharan self-efficacy and sexual risk behaviour studies found evidence for the effect of self-efficacy on condom use in young men, and sex refusal in young women and men (Closson et al., 2018). However, the evidence currently does not distinguish whether self-efficacy acts as a mediator, determinant, or cause of behavioural change and maintenance (Young et al., 2014).

Bandura later commented that, while threat may initiate an adaptive behavioural response, equally, "People fear and tend to avoid threatening situations they believe exceed their coping skills, whereas they get involved in activities and behave assuredly when they judge themselves capable of handling situations that would otherwise be intimidating" (Bandura, 1977a, p 194). According to Bandura, self-efficacy and environmental facilitation greatly influence health behaviour. When designing health interventions, designers should consider the impact of the architecture of the environment in encouraging easily adoptable behaviours.

Bandura, however, wrote frequently about the chance encounters that precipitate changes in life course. While fortuitous factors can greatly impact one's life course, these factors have just recently become the focus of study in the field of behavioural economics (Ariely & Loewenstein, 2006; Thaler & Sunstein, 2008). Since cognitive models are highly reliant upon deliberative thinking and behaviour, which is evidently often not the reality (Hardcastle et al., 2015), alternative models have been developed to specifically describe counterintuitive behaviour when there are competing priorities, and to design interventions that account for irrational behaviour.

Brain, behaviour and motivation

Since traditional behaviour change intervention through educational messaging is limited in its ability to influence health-seeking behaviour towards the adoption of efficacious testing, prevention and treatment methods, what are the important factors that motivate human behaviour? Human motivation is well researched (Becker, 2007; Shah & Gardner, 2008). We understand that people are broadly motivated to 1) fit into a social group and to 2) be recognised for socially valued characteristics, roles and actions (Becker, 2007); our intelligence, our work, our possessions, our family, our group affiliation, our status, or our generosity. Exceptionalising negative aspects of identity, such as sexual risk-taking leading to ill health and the potential consequence of death, may be ineffective because it can negate both motives. Consequently, it is important to understand how young people think about risk, pleasure and sex.

Neuroscientific research has investigated brain development and sexual risk-taking (Victor & Hariri, 2016). The development of the limbic system and the periaqueductal grey precedes prefrontal cortex development in early adolescence (Catani, Dell'Acqua, & De Schotten, 2013). The limbic system is responsible for emotion and motivation, specifically pain-avoidance and pleasure-seeking through rewards, appetite and sex. Forebrain development of the prefrontal cortex, which is associated with behavioural control, follows later in late adolescence and stabilises in early adulthood (Sawyer et al., 2012). Even though most adolescents are capable of adult decision making and can pre-contemplate sexual encounters, the amygdala (limbic system) can overwhelm behavioural control of the under-developed prefrontal cortex and it is frequently evident that forethought does not translate into protective behaviour (Victor & Hariri, 2016). The gap between adolescent and adult identity and social roles, and the cognitive capacity to project consequences and deal with the economic and social implications of sexual behaviour holds a period of vulnerability for AYA in the form of unintended consequences; pregnancy, sexually transmitted disease and sequelae, and mortality.

Though adolescents can reason about risk much like older adults, fore-reasoning is less likely to increase risk aversion when actually faced with risk behaviour. Present desirability tends to outweigh future benefit or risk during this period more so than in middle-adulthood. Health models predict that threat information during a period of high need for affiliation and an inclination to weigh reward over risk will increase vulnerability-denial and may even increase risk behaviour for those who value that risk behaviour. Peer approval within a context of high peer risk behaviour has real potential to encourage risk behaviour (Arnett, 1992). In addition to being prone to consider rewards over risks, evidence from psychological research validates the neuroscientific data in finding that optimistic bias is amplified in adolescence (Arnett, 2000). Moreover, the need for affiliation and peer affirmation powerfully affect behaviour throughout the lifespan, but the inclination to weigh the short-term affiliation goals over long-term goals is more pronounced during adolescence. The following section explains how affiliation affects behaviour.

Context and affiliation drive behaviour in adolescence

Short term desires frequently conflict with longer-term goals, such as self-presentation through status and affiliation, which is amplified when mortality is salient (Wisman & Koole, 2003). Wisman and Koole ran an experiment investigating the effect of mortality salience on affiliation with others. The experiment showed that participants made aware of their mortality were significantly more likely than control condition participants to disregard their personal ideological beliefs of tolerance and affiliate with a group who held opposing views! Being made aware of their mortality caused participants to identify with others who were explicitly identified as intolerant.

As affiliation is increasingly self-directed and becomes sexual in adolescence, this period of vulnerability is evidenced by high (Zuma et al., 2010) and increasing levels of self-reported early sexual debut (sexual debut before 16 years) (Shisana et al., 2014; Zuma et al., 2016). Despite high awareness of HIV risk, risk behaviour had increased in South African AYA as evidenced by the large-scale HIV population survey conducted by Shisana and colleagues. Adolescents may well be motivated to deny vulnerability to HIV because it is uncomfortable to hold that one is at risk of wasting and death, which conflicts with desirable outcomes. This is particularly problematic because early sexual debut is associated with increased risk of HIV infection and South African adolescents have been especially vulnerable to HIV infection. Policy makers and healthcare practitioners have puzzled over how to support adolescents through this period through increasing health-seeking and healthy outcomes, and how to lower risk behaviour and the potentially long-term effects of unwanted pregnancy, disease and mortality.

The risks and stressors in South African limited resource communities are numerous, including violence, economic adversity and disease. High-risk environments place cognitive processes under strain, resulting in constricted thinking and behavioural repertoires. The strain is the result of constant vigilance of threats on life-expectancy. The biological necessity of survival (including sexual risk) is prioritised in high risk environments over long-term outcomes (Figueredo et al., 2006; Figueredo & Wolf, 2009). In low risk environments survival threats are protected against and negotiated; behaviour is less governed by risk avoidance in low risk systems, but by increasing gratification of longer-term goals. Behavioural economists have investigated these systematic flaws which lead to counterintuitive behaviour and have used the research to improve the chances of healthy, desirable outcomes.

Behavioural Economics: from rationality models to predictable irrationality

Behavioural economics was developed to account for the effects of psychological, social and contextual factors on human behaviour because traditional economic theories had customarily studied purely rational (fictional) humans, referred to as rational optimisers or homo-economicus (or econs, for short) (Rice, 2013; Thaler, 2000; Thaler & Sunstein, 2008). Econs are characterised by unbounded rationality, rational expectations, perfect calculating abilities and perfect self-control, which leads to rational decisions and perfect behavioural execution. But human rationality is limited (Simon, 1955, 2000). Humans are not merely fallible in irrationality, but rather, we make systematic and predictable mistakes "… that make us gullible and prone to believe too strongly whatever we believe" (Kahneman, 2011, p 122). People often adopt self-defeating behaviours, such as being sedentary, overeating, drinking too much, smoking and engaging in risky sex (Bland, An, Foldes, Garrett, & Alesci, 2009; Loewenstein, Brennan, & Volpp, 2007; Myers, 2010). Additionally, many diseases and other health problems are exacerbated by unhealthy behaviours or failing to adopt healthy ones (Loewenstein et al., 2007; Myers, 2010). Low rates of adoption diminish the potential of lifesaving disease detection, prevention and treatment, such as ART and PrEP. Behavioural economics has been used to identify systematic and predictable patterns to decision-making errors and biases, and to develop ways of improving beneficial outcomes, such as public health (Thaler & Sunstein, 2008).

Knowing that people are predictably irrational when required to consider health behaviours that simultaneously reduce preventable outcomes and which potentially provoke anxiety, what can we do to increase health-seeking behaviours? Behavioural economists recommend that libertarian paternalism could be used in multiple ways to improve public health. Once patterns to counterintuitive behaviour have been established, choice architects can design choices that improve health behaviour (Johnson & Goldstein, 2003; Thaler & Sunstein, 2008). The term libertarian

paternalism is foundational to behavioural economics and is demonstrated by the well-known cafeteria illustration (Thaler & Sunstein, 2008). Imagine that a friend, Nomsa, is the director of public school cafeterias across the province. A new government policy has recommended that school cafeterias introduce healthy food options. While the traditional menus which include more processed foods consisting of refined carbohydrates will not be removed from the menu, Nomsa must decide on the presentation of the new options in school cafeterias. Even though Nomsa will not remove older menu options, she decides that she will run a few experiments with three different presentation styles to implement the new menu: 1. randomly present the food, 2. maximise the chances of students choosing healthy options, and 3. maximise profit.

As a choice architect, Nomsa has the responsibility of organising the environment in which people make decisions (Thaler & Sunstein, 2008). Just like traditional architecture, there is no neutral design because architects design buildings to work towards a purpose. By changing the food presentation order, Nomsa could increase the uptake of specified options. While option 1 was less intrusive, students were more likely to benefit from option 2. Nomsa could have chosen option 3 to maximise profitability and sustainability, but since Nomsa is concerned that the choice maximises health benefit for the students, she decided to implement option 2. Option 2 nudged students towards healthy food without removing less healthy options.

If one can nudge towards benefit through designing choices, ethically, one should. Governments and businesses have used nudges to effectively curb self-defeating behaviours (non-adherence to chronic medication, Linnemayr & Stecher, 2015), improve beneficial behaviours (increase saving, Thaler and Sunstein, 2008, p.112, 130), reduce cost (reduction in urinal spillage, Thaler and Sunstein, 2008, p. 4) and facilitate scale (increase organ donations, Thaler and Sunstein, 2008, 175). Findings from the field of HIV showed that, prior to a behavioural economics intervention, patients were more likely to focus on the present hassle of taking treatment than the long-term benefit of not getting sick (Linnemayr & Stecher, 2015). To counter non-adherence, Linnemayr and Stecher (2015) implemented a lottery in which patients could participate if their drug levels were acceptable. The study found that the lottery intervention, tailored for predictable errors in decision-making, significantly improved adherence. There are a number of such biases which lead to errors in decision-making, but broadly these are related to diminishing the discomfort associated with cognitive dissonance (Festinger, 1962). When psychological equanimity falters due to cognitive dissonance, humans work to remove the psychological discomfort instead of acting to reduce harm and improve wellness.

Though most disease-related mortality can be avoided by healthy behaviour, people often behave in ways that exacerbate morbidity and mortality. We avoid screening and health services because it

helps assuage anxiety and deny vulnerability associated with disease and death. South African adolescents are no exception to this problem and require innovative interventions that will facilitate health-seeking and improve HIV-related outcomes. The overview presented above sets the theoretical foundation upon which effective behavioural change programs have been designed and implemented and will be used to outline an approach to improving health-seeking in South African AYA.

Thesis overview and structure

Summarily, people often behave counter-intuitively, against maximising personal utility, because we are prone to avoid discomfort and maximise present benefit, even if those goals conflict with longer-term priorities. To achieve this, we discount both dissonant information and the future, and place too much emphasis on information and experiences that agree with our bias and on the present (Kahneman, 2011). Our supposed insight is misleading us in repeatable and predictable ways. Knowing that people behave in predictably irrational ways, how do those involved in healthcare policy and service offer options that will facilitate health-seeking behaviour? Specifically, how do we encourage young South Africans who are most at risk of HIV infection and HIV-related mortality to adopt SHS?

SHS are currently not adapted for uptake in young people, partly because of their adult-centric nature, the multiple barriers discussed, and the overreliance upon autogenerated, consciously deliberate health-seeking behaviour in response to information campaigns. While the barriers to uptake of SHS among South African AYA are well described (Bekker et al., 2015; Black et al., 2014; Geary et al., 2014; Strauss et al., 2015; Wood & Jewkes, 2006), few studies have engaged in iterative, participatory research with this group to investigate and implement desirable and acceptable services. In line with the objectives of the research, the studies that follow set out to investigate more desirable, contextually adapted sexual healthcare services to improve acceptability and uptake among young people. The participatory research studies were designed to provide options that were desirable, convenient, easy to adopt and use, were tailored for the specific population, and which sought to build trust with AYA. The behavioural economics model was used to frame the iterative, participatory research.

Specifically, the studies set out to lean on system 1 thinking (figure 1, p. 11) to enhance health-seeking in AYA. Traditional health models tend to rely upon system 2, deliberative, effortful, and logical decision-making processes to encourage health-seeking. As described, behavioural models must improve the impact of interventions that seek to encourage health-seeking, and more so in AYA where HIV-related health outcomes are so poor. The studies that follow have used characteristics of system 2 thinking, relying upon reducing effort on the part of the patient, reducing time required, enhancing

automaticity, improving the quality of positive emotion (through relationships) to enhance health-seeking behaviour.

System 1	System 2
Instinctive	Conscious
Little/ no effort	Effortful
Quick	Slower
Emotional	More logical
Automatic	Deliberative
No sense of voluntary control	Complex decision

Table 1: Behavioural economics two systems of thinking

Current research suggests that interventions should aim at providing services that improve convenience and ease-of-use, and personal interactions with healthcare staff should offer a trusting relationship directed at aligning the clients desired outcome with efficacious intervention. The work presented in this thesis commenced with participatory research to understand desires and preferences of AYA with regards to SHS. Thereafter, three interventions were designed with behavioural economics principles in mind; the first was a specific health delivery platform, the second was novel diagnosis and screening, and finally, a prevention intervention. Each of the studies presented in Chapters 2 to 5 are also adapted from published papers, as indicated at the start of each Chapter. We hypothesised that implementing adolescent-friendly services that emphasise privacy, confidentiality and trust, and improved convenience, would be desirable characteristics of acceptable SHS that would increase the uptake of these services in at-risk young people.

Chapter two: Convenience, tailoring and trust-building at sexual health services are high priorities for young people: Participatory research with South African adolescents want in sexual health services

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Abstract

Background: Young people in sub-Saharan Africa are disproportionately affected by HIV, sexually transmitted infections and unplanned pregnancies. The provision of accessible sexual health services (SHS) for young people in SSA is vital to reduce this burden. This study examined the needs of South African adolescents regarding differentiated, accessible and adolescent-responsive SHS.

Methods: Data were drawn from a larger project examining the feasibility of conducting HIV vaccine trials in adolescents. Fifteen focus group discussions were conducted across five research sites, with 120 male and female adolescent HPV vaccine trial participants aged between 12–19 years from four South African provinces in low income areas with high HIV incidence. Transcribed data were double-coded using framework analysis.

Results: Three main themes emerged for how best to improve SHS for adolescents in resource-limited settings. Participants highlighted the need for adolescent-friendly services, availability of developmentally appropriate and tailored information, and improved relationships between healthcare workers and clinic attendees. Participants wanted more flexible opening hours at SHS to account for travel time to clinics from school and home. Participants suggested services include contraception, counselling, educational materials, links to adoption services, emergency vehicles, pre- and post-natal care and improved service quality from clinic staff.

Discussion: Whilst dedicated adolescent SHS might best meet the needs of young people in South Africa, this study suggests that failing this, then existing SHS should be more responsive to adolescent use. Innovations such as mobile outreach services, self-testing and flexible hours can provide adolescent-responsive SHS.

Introduction

South African adolescents are at substantial risk of HIV infection due in part to the psychosocial and biological transitions experienced during this developmental phase whilst living in an area of high HIV burden (Bekker et al., 2015; Pettifor et al., 2013). While HIV incidence and HIV-related deaths have decreased in other populations in sub-Saharan Africa, HIV-related deaths amongst adolescents continue to rise (Delany-Moretlwe et al., 2015; Dellar, Dlamini, & Karim, 2015; Geary et al., 2014)(Delany-Moretlwe et al., 2015; Dellar, Dlamini, & Karim, 2015; Geary et al., 2014). The development of sexual identity and sexual debut during this period are associated with the risk of sexually transmitted infections (Dickson-Tetteh et al., 2001; Geary et al., 2015) and unplanned pregnancies, with 18% of 10 - 19 year olds and 27% of 15 - 26 year olds in South Africa reporting at least one previous pregnancy (Christofides et al., 2014; Macleod & Tracey, 2010).

During this period, adolescents are keen to become better informed about sex and its potential consequences, but may avoid healthcare services because of both real and perceived barriers (Bekker et al., 2015; Black et al., 2014; Geary et al., 2014, 2015; Jewkes, Morrell, & Christofides, 2009; Svanemyr, Amin, Robles, & Greene, 2015; Vujovic, Struthers, Meyersfeld, Dlamini, & Mabizela, 2014; Wood & Jewkes, 2006). While some adolescents visit general practitioners for their sexual and reproductive health needs (MacPhail & Campbell, 2001), many are unaware of the range or location of clinics offering sexual and reproductive health services (Dickson-Tetteh et al., 2001). Barriers to accessing healthcare include fragmented healthcare services, long travelling and waiting times and fears around interactions with healthcare staff, such as fear of embarrassment, interactions with judgmental staff, loss of confidentiality, privacy and fear of being examined (Mmari, Marshall, Hsu, Shon, & Eguavoen, 2016; Vujovic, Struthers, Meyersfeld, Dlamini, & Mabizela, 2014; Wilson & Williams, 2000). The availability of differentiated, welcoming and accessible SHS for adolescents must be prioritized in order to address the needs of young people (Dickson et al., 2007).

A systematic review of adolescent-friendly SHS in Sub-Saharan Africa reported on the gap between the numbers of HIV-affected youth (either those at risk of HIV or those living with HIV) and the interventions available to support them (Michielsen et al., 2010). Systematic reviews from South Africa point to non-judgemental provider interaction and confidentiality as primary desirable characteristics for youth-friendly services (Geary et al., 2014; Zanoni, Archary, Buchan, Katz, & Haberer, 2016). In response, NAFCI (**Chapter one, page 20**) was developed in South Africa between 1999 and 2006 to support clinics to provide more adolescent-friendly services (Dickson-Tetteh et al., 2001; Geary et al., 2014). The NAFCI received mixed reviews, in that while the clinics earmarked as adolescent-friendly clinics were considered more responsive in the provision of adolescent services,

adolescents did not report an increase in positive interactions with staff (Mathews et al., 2009). NAFCI was subsequently discontinued, primarily due to a lack of sustained funding (Pettifor, MacPhail, Bertozzi, & Rees, 2007; Pillay, 2001; Schriver, Meagley, Norris, Geary, & Stein, 2014). More than 20 years into the South African HIV epidemic, this generation of youth have not known a world without HIV and it is important to examine their concerns, needs and perceptions regarding sexual, reproductive health and HIV prevention and treatment services such as HIV Counselling and testing (HCT), referral to ART and Pre-exposure Prophylaxis (PrEP), and voluntary male medical circumcision (VMMC).

Since AYA generally perceive themselves to be in good health, they are prone to delay or avoid health-seeking. This is paired with the contextual high burden of HIV and STIs and the high cost of accessing healthcare services, such as anticipated stigma, financial cost, time constraints and fears about a positive diagnosis. Consequently, young people perceive health-seeking to be inconvenient and a greater cost than the benefit of delaying. The behavioural economics framework suggests that making access more convenient and easier to use can improve uptake. Using iterative and participatory research framed by the behavioural economics model, we sought to design and implement SHS adapted for young people.

The present study was a sub-study of a larger project, the South African Studies on HIV in Adolescents (SASHA), studying the feasibility of conducting HIV vaccine trials in adolescents (Wallace et al., 2018). The first study asked young people what they wanted in SHS to inform the design and implementation of tailored services with the intention of offering SHS to AYA in high disease burden areas before illness compels a clinic visit. Given the importance of youth engagement in the provision of user-friendly services for this population, the present project set out to investigate adolescent preferences for differentiated sexual and reproductive health services with the aim of finding innovative ways to tailor adolescent-friendly services and improve responsiveness to AYA in the healthcare infrastructure.

Methods

Data were collected from adolescent focus group discussions (FGDs) with participants from around South Africa. Prior to the FGDs, participants gave their written informed consent, including consent for audio recordings of the FGD. Parental consent was sought for participants who were younger than 18 at the time of participation.

Sample and setting – The research was conducted at five clinical research sites in South Africa: the Desmond Tutu HIV Foundation's Emavundleni clinical research site in Crossroads, Cape Town (DTHF);

the Centre for the Aids Programme of Research In South Africa (CAPRISA) in Durban; the Perinatal HIV Research Unit (PHRU) in Soweto, Johannesburg; Mecru Clinical Research Unit (MeCRU), at Sefako Makgatho Health Sciences University (the former Medunsa Campus of the University of Limpopo) in Pretoria; and the Aurum Institute in Klerksdorp and Rustenburg (KOSH). These research sites are located in predominantly low-income areas with high HIV incidence. Each site's Institutional Review Board granted ethical approval for the study (University of Cape Town reference 245/2008, University of Witwatersrand reference 080710, University of KwaZulu-Natal reference BF109/08, University of Limpopo reference MREC/P/110/2009).

Adolescents between 12 - 17 years old were recruited from the main cohort study, which used community outreach activities in sports clubs, transport hubs, community centres, HIV voluntary counselling and testing services and other public spaces. Since it was anticipated that the needs of younger and older adolescents and of males and females might differ, participants were given the choice between attending age specific and single-sex discussion groups, or mixed groups. There were 15 FGDs with a total of 120 participants (54 male, 60 female, 6 unspecified) across five sites (Table 2).

	Group 1		**Group 2**		**Group 3**	
Location (number of FGs)	**Co-ed Groups**		**Female Groups**		**Male Groups**	
Cape Town Desmond Tutu (2)	12-17 years	n=11 (5f 6m)			12-15 years	n=6
Johannesburg, PHRU (4)	12-15 years	n=6 (unspecified)	2x 12-15 years	n=9 n=8	15-17 years	n=10
Klerksdorp, KOSH (3)	12-15 years	n=5 (4f 1m)	15-17 years	n=6	12-16 years	n=5
Durban, CAPRISA (3)	15-17 years	n=11 (5f 6m)	16-17 years	n=11	12-15 years	n=8
Pretoria, MeCRU (3)	15-17 years	n=8 (4f 4m)	12-15 years	n=8	15-17 years	n=8

Table 2: Summary of participants per site

Picture(s) 1: Images of focus group discussions

Trained community educators conducted the FGDs at the research sites. A facilitator presented ten questions designed to gauge adolescent perspectives on adolescent-friendly healthcare services, and

group members generated and explored their own understandings of what kind of healthcare services were required for good sexual health.

Conceptual mapping was used to facilitate discussion of adolescents' opinions. This process requires participants to map responses on paper by grouping similar desirable characteristics together (Latka, Kapadia, & Fortin, 2008). The requirements of a SHS were grouped according to services desired (e.g. pregnancy testing) and characteristics of that service (e.g. non-judgmental atmosphere). Participants were asked to explain the rationale underlying the organisation of their responses. This method has been particularly helpful in initiating and focusing discussion around sensitive topics, and in eliciting information from participants who tend to be more visually orientated (Latka et al., 2008). In this study, conceptual mapping identified characteristics of an adolescent-friendly healthcare service, and allowed participants the freedom to generate their own values on the discussion topic.

Data Analysis – The FGDs were conducted in the local languages and were audio recorded. After the audio was transcribed, the transcriptions were translated into English. Nine representatives from the five sites were trained to code the FGDs, develop coding charts and map the data. Double-coded charts were analysed using the framework method of analysis. This provided a procedural structure for organising data into key emerging themes to support data familiarisation, identification of themes, indexing themes and data interpretation. Coders held regular calls throughout the analysis process to ensure consistent coding and to discuss emerging themes and adapt coding charts.

Results

Overview of the focus group discussions: four themes

The data from the focus group discussions were framed into the following four categories: 1) The need for the provision of dedicated adolescent health services, 2) Tailored services with developmentally appropriate information, 3) Emphasis on the desire for confidentiality and trusting relationships with healthcare staff, 4) Greater emphasis on appropriate services required at an adolescent clinic.

Dedicated adolescent services

Participants expressed negative sentiments about the routine care young people experience at government clinic facilities, reporting that clinic opening times are inflexible, staff can be unpleasant, stigmatising and often rude, that staff did not respect confidentiality and gave inappropriate and misleading information. One participant noted:

> F16-17 "Because most young people are disturbed already, a young person is not able to go to the public clinic because nurses there are very rude."

Participants universally agreed that friendly adolescent services were needed. They suggested that dedicated services would result in less discrimination towards younger people with a reduction in perceived and actual stigma. Participants were enthusiastic about the concept of dedicated adolescent health services, and reported that adolescent services would "…change people's lives in regard to the issue of assistance in the clinic." Participants also stated that they would feel more comfortable and *"… free with their own age group who are understanding."*

> M15-17: *"*It's okay if we will not feel shy and become free, if we can be understood by staff. Younger staff can understand challenges facing adolescents and address our issues as adolescents. They must be able to talk to people. One can go to the clinic and find that there are staff that are not kind or sensitive."

Tailored services

Adolescents wanted tailored information and services directed at their specific developmental stage. Didactic and punitive commands issued by clinic staff were specifically noted as being unhelpful. Participants felt that staff could encourage healthy behaviour if they were open to listening to young people, could connect with common issues faced by adolescents, could give relevant practical advice, and could suggest ways of navigating potential barriers to health. The suggestion of younger staff and possibly peers to act as guides to help navigate the services was also made. Group members noted that it was important for information to be appropriate for their age and tailored to their needs.

> F16-17: "As for me, I would feel much better that I am going to the youth clinic than going to a community clinic because I will be able to even get tested for HIV because I would feel more comfortable than going to the adult clinic… I also think that it will be something right to have a youth clinic because you will be comfortable to speak with the people."
>
> M12-15: "Our clinic needs to have young staff to welcome us and be able to talk to us in an appropriate manner and treat us with respect and care. To have people who know how to talk to young people if they are traumatised."
>
> M12-15: "They need to talk to the counsellor or people who know these issues, because if they go to traditional healers they will get herbs that are not good."

Relationships: confidentiality and trust

When asked about what they want from a healthcare service, participants noted that trust in staff and health facilities is an important factor. Participants reported that health facilities are daunting places where they may see people they know, leading to actual or perceived loss of confidentiality. Adolescents feared specifically that their parents would find out that they had attended a clinic which consequently discouraged attendance. Participants stated that mistrust leads to less honest sharing

of information, but that trusting relationships would foster honest conversation with healthcare professionals.

> F16-17: "I think that you end up changing the story, as you enter through the door you say no, I will tell the truth, but then when sitting down with the person you change the story because when the nurse you talk with is about to go through the door, she is telling another nurse who is in another room "But the children of today they are like this, look at the one here, [she] has slept with boyfriends", but there are people there at the same time… by the time you go out that door you are known to be sexually active or pregnant at the age of 13 or so."

Adolescents thought that dedicated services could provide adolescents with safe spaces to share their issues and problems with staff, without fear of reproach, with one participant stating *"… it will help people to feel safe emotionally and physically."*

Adolescents said they were unlikely to *"… go if they feel judged*" or if older people lectured them and spread rumours about them. Adolescents felt their sexual behaviour was stigmatised and therefore were not fully informed of their options by clinic staff. Participants feared clinic staff and felt uncomfortable disclosing sexual activity and asking healthcare staff for services.

Availability of appropriate services and information

Participants were most vocal about contraception services and related education, stating these services should be available and confidential. Additionally, participants were interested in individualised contraception options, instead of receiving a 'one-size-fits-all' approach. Participants suggested that women should have access to private rooms where contraception can be made available. Adolescents recognised the need for accurate information in making health decisions with a female participant commenting: "*…it is better to get information from experienced adults like your mother or health staff.*" However, participants reported that information given to adolescents visiting traditional facilities was not always age-appropriate and was sometimes inaccurate. Participants believed that clinic staff did not always present them with all of the information, or all of the available options. Participants said that healthcare staff should be up to date so as to provide reliable, tailored and relevant information. Additionally, participants indicated that sexual and reproductive health services should provide pre- and post-natal care, information about adoption services and emergency vehicles which are differentiated for AYA. Additionally, while emergency contraception is available as standard of care at conventional clinic facilities, this should carry through to services differentiated for adolescents. Participants stated that it was important to receive counselling around contraception and STI prevention. The suggestion was made that counselling be available for adolescents who needed rehabilitation for drug use.

Discussion

Whilst FGD participants expressed the need for distinct adolescent clinics, many of their needs could be met via adaptations in mainstream clinic services if provided with youth needs in mind. Poor interactions between adolescents and clinic staff creates mistrust in young people using the health services, which may lead to inappropriate or inadequate care. If young people do not use sexual and reproductive health services due to negative perceptions of these facilities, the opportunity for HIV, STI and pregnancy prevention and care is lost. Since adolescent clinic attendees regularly report poor experiences at health facilities and feeling discriminated against, one adaptation could be the adoption of peer navigators as a standard cadre of staff in clinics serving youth.

The content of the FGDs aligned with previous qualitative data (presented in Chapter one) on adolescents' desires for adequate healthcare services (Forrest et al., 2009; MacPhail et al., 2008; Ntsepe et al., 2014; Tylee, Haller, Graham, Churchill, & Sanci, 2007; Wood & Jewkes, 2006). It was clear that young people want accurate age appropriate health information and client centred care. They expressed the desire to talk openly and ask questions without fear of being stigmatised or judged. Participants spoke in depth about the quality of care being enmeshed in trusting relationships between service users and healthcare professionals. Participants also spoke at length about the difficulties of expressing themselves to healthcare staff, and emphasised the need for spaces where they could speak openly to people who they felt could relate to them. In addition, participants want accessible and relevant services that preserve their privacy and confidentiality. These youth-friendly spaces may increase health-seeking behaviour.

While the study findings may have good generalisability because the data were collected from a variety of locations across South Africa, the adolescents and parents who were willing to participate in the research in the acceptability of a vaccine for an STI may be more open than the general population. Willingness to participate in sexual health research may indicate that this was a subset of the general population who were more informed and forward-thinking regarding sexual health.

NAFCI attempted to address a number of the issues that were raised by the participants in this study, including the provision of sensitivity training to NAFCI staff, the provision of a youth-friendly space and accompanying peer support through youth "ground breakers" provided by the loveLife HIV prevention project (Pettifor et al., 2007). As discussed in Chapter one, the scale-up and sustained presence at government clinics was challenging due to a lack of coordination and resourcing in a decentralised health system in South Africa (Pillay, 2001; Schriver, Meagley, Norris, Geary, & Stein, 2014). Analysis of NAFCI showed that while adolescents were more likely to receive HIV testing at

NAFCI clinics, the overall experience of these clinics was no more positive than at non-NAFCI clinics, because patient-provider relationships, confidentiality, and the appropriateness of counselling services were rated similarly at NAFCI and non-NAFCI clinics (Geary et al., 2014; Mathews et al., 2009). Adolescent-friendly services should specifically address these important issues to attract more adolescent visitors. Adolescents who had participated in two or more loveLife programmes were less likely to acquire HIV infection (Pettifor et al., 2005), and NAFCI clinics were more likely to provide HIV testing to adolescents. The valuable lessons learned from NAFCI could inform future investigations and the implementation of scalable and sustainable innovations for adolescent-responsive healthcare.

The results of this study are relevant to objectives 2 and 3 of the South African youth health policy, specifically the recommendation for the provision of adolescent-friendly services including comprehensive and integrated SHS and HIV prevention, testing and treatment services. Adolescent-responsive health services with 'youth zones' have the potential to encourage regular health-seeking and prevent unwanted outcomes in adolescents. These spaces could also be used to offer additional biomedical prevention services, such as PrEP and VMMC as recommended in the South African guidelines. Providing these services in spaces that have been designed for AYA has the potential to improve the suboptimal rates of HIV testing, treatment and prevention initiation (HSRC, 2018).

Implementation research was done and is included in Chapters three to five. These Chapters focused on bringing the lessons learnt from this study and from previous initiatives together in services that meet young people at the point of their need. Emphasizing aspects of confidentiality and non-judgemental staff could attract more youth to services, particularly those services most relevant to young people. This could be implemented by having clinic based or community-based peer navigators who themselves have been well-trained youth or young adults that demographically match or are close to the adolescent target population. Stationed at the clinic or deployed into the community these youth could relay the message that the clinic is different and non-judgemental and trustworthy whilst also helping adolescents understand what services are available and how best to use them. Differentiated healthcare delivery methods that improve engagement with SHS, such as mobile clinics (Chapter three) and self-testing (Chapter four) should be explored to improve HIV testing uptake, which is increasingly the gateway to healthcare services in limited resource communities. Mobile services are cost effective and can be monitored to direct the clinic to communities most in need of the service (Bassett et al., 2014, 2013; Mavedzenge, Baggaley, & Corbett, 2013). Healthcare services could also consider the use of mobile technology to extend the patient-provider relationship and communicate with patients based on their personal health profile (Perry et al., 2012). This technology could be incorporated into existing services and could rely on instant messaging platforms that are

relatively inexpensive. Individualised care has been found to be more acceptable than general services amongst adolescents (Forrest et al., 2009; Kaufman et al., 2016). Additionally, future research could investigate the effects of a gain-framed, wellness-centred approach to behaviour change that builds a sense of autonomy and competence through providing responsive sexual and reproductive health options for adolescents. Finally, cost, feasibility and scalability should be urgently investigated to ensure that such programs are well-designed, adopted, integrated and become entrenched in national public health provision. As previously discussed, financial commitment is crucial to prioritise health promotion and

Young South Africans are concerned with their health but are put off from visiting conventional health facilities which tend to be stigmatising, time consuming and unhelpful. The health system remains largely disinclined to catering to AYA specific sexual and reproductive health needs, which places AYA at risk of acquiring HIV, unintended pregnancy, other STIs and undermines their overall health and wellbeing. Taken together, the results of this study suggest that adolescents would benefit from tailored models of care, including diagnostics, counselling and support through adolescent-directed sexual health options for prevention, treatment and care. Since dedicated adolescent services in South Africa may only be a future consideration, adolescents may benefit from the implementation of scalable, integrated SHS within the existing health infrastructure. Successfully integrated, adolescent-friendly HIV prevention and SHS can in turn provide a gateway to lifelong healthy engagement with health services.

When designing adolescent-friendly services, behavioural economics research recommends considering how designing health services could nudge behaviour towards healthier outcomes. Since people in general, and adolescents specifically, could do better in making healthy choices, policy makers and implementers should consider designing healthcare services that at the very least, do not lower health-seeking behaviour, and at best, improve uptake and reduce unwanted outcomes. Frequently, we think of those who use healthcare services like rational decision-makers who "… can think like Albert Einstein, store as much memory as IBM's Big Blue, and exercise the willpower of Mahatma Gandhi. Really" (Thaler & Sunstein, 2008, p 6). While one cannot claim that every person who experiences an unwanted outcome is not thinking rationally, one cannot however state that everyone is rationally choosing to eliminate risk. Since providing information alone has very limited impact upon increasing health-seeking behaviour and since young people are reluctant to seek out health services, behavioural economics research suggests we should design choices that make engaging health systems more desirable to youth. The next three chapters outline some interventions that attempt to do this, including their strengths and limitations.

Chapter three: Tailored, adolescent-friendly mobile clinic sexual health services are convenient, trust-building, and highly preferred over conventional clinics: a health delivery platform differentiated for adolescents and young adults

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Abstract

Background: The Human Immunodeficiency Virus (HIV) epidemic is growing rapidly among South African adolescents and young adults (AYA). Although HIV counselling and testing, HIV prevention and treatment options are widely available, many AYA delay health-seeking until illness occurs, demonstrating a need for youth responsive, integrated sexual and reproductive health services (SHS). While feasibility and cost-effectiveness have been evaluated, acceptability of mobile clinics among AYA has yet to be established. The objective of this study was to investigate patient acceptability of mobile AYA SHS and compare mobile clinic usage and HIV outcomes with nearby conventional clinics.

Methods: Patients presenting to a mobile clinic in Cape Town were invited to participate in a study investigating the acceptability of the mobile clinic after using the service. A trained researcher administered a questionnaire-based acceptability survey. Mobile clinic medical records during the study period were compared with the records of AYA attending four clinics in the same community.

Results: 303 enrolled participants (16-24 years, 246 (81.2%) female) rated mobile AYA SRHS acceptability highly (median = 4,6 out of 5), with 90% rating their experience as better or much better than conventional clinics. The mobile clinic, compared to conventional clinics, attracted more men (26% v 13%, p<0,000), younger patients (18 v 19 years, p<0,000), and yielded more HIV diagnoses (4% v 2%, p<0,000).

Discussion: Given the high ratings of acceptability, and the preference for mobile clinics over conventional primary health clinics, the scalability of mobile clinics should be investigated as part of a multipronged approach to improve the uptake of SRHS diagnostic, prevention and treatment options for AYA.

Introduction

Adolescents and young adults (AYA, 10-24 years) commonly express a desire to find out more about sex and sexual health, but tend to avoid sexual and reproductive health services (SRHS) because they experience real and perceived access barriers (Bekker et al., 2015; Black et al., 2014; Geary et al., 2014, 2015; Shamagonam James et al., 2018; Svanemyr, Amin, Robles, & Greene, 2015) . Barriers regularly cited involve anticipation of embarrassment, fear of loss of privacy, and fear of physical examination (Strauss et al., 2015). Although some AYA may visit pharmacies and general practitioners, these alternative services may be out of reach because they are practically inaccessible due to cost, far traveling distance or the long time required for visits (Dickson-Tetteh et al., 2001). Many young South Africans only enter healthcare once ill and in need of care (Hosek et al., 2016; Strauss et al., 2015; K. Wood & Jewkes, 2006).

The unique psychosocial and biological transitions place AYA in high disease burden communities at significant risk of human immunodeficiency virus (HIV) acquisition (Bekker et al., 2015; Hosek et al., 2016; A. Pettifor et al., 2013; Victor & Hariri, 2016). Sexual debut (Simbayi et al., 2004; K. Zuma et al., 2010) and developing sexuality both occur during this developmental phase and frequently co-occur with sexually transmitted infections (STIs) (Barnabas et al., 2014; Dickson-Tetteh et al., 2001; Geary et al., 2014) and unintended pregnancies (Christofides et al., 2014; Macleod & Tracey, 2010; Mkhwanazi, 2012). While HIV incidence and related mortality have declined in recent years (Williams, Gupta, Wollmers, & Granich, 2017), South African AYA have not experienced the same declines (Delany-Moretlwe et al., 2015; Dellar et al., 2015; Geary et al., 2014; Moodley, Gray, & Bertram, 2016).

Despite the recommendation to improve HIV testing in key populations (Shisana et al., 2014), many AYA living with HIV remain unidentified until symptomatic (Goldenberg, Arndt, Hart, & Routledge, 2008; Govindasamy, Ford, & Kranzer, 2012; Mulaudzi et al., 2018; K. Wood & Jewkes, 2006). The global scale-up of antiretroviral treatment (ART) has dramatically improved the quality of life for many people living with HIV. In combination with biochemical prevention methods, such as pre-exposure prophylaxis (PrEP), access to ART programs can significantly curb the HIV epidemic. Attaining this ambitious goal requires innovation that links young South Africans to SRHS, including diagnosis, prevention, treatment, adherence and viral suppression (Bastani et al., 2010; Bekker et al., 2015; Pop-Eleches et al., 2011; Velasco-Hernandez, Gershengorn, & Blower, 2002; Zanoni et al., 2016). With this in mind, youth-friendly services have been recommended for AYA (Dickson et al., 2007; Strauss et al., 2015; Tylee et al., 2007; WHO, 2012). Youth-friendly services typically have been specifically designed for youth, or are conventional health facilities that have been adapted to serve AYA by providing tailored information and care that is appropriate to the developmental stage (Pettifor et al., 2018).

Adolescent responsive mobile clinics that offer integrated health services could ideally link potential patients to conventional clinics, and thus achieve more timeous risk reduction and treatment initiation (Govindasamy et al., 2015; van Schaik et al., 2010). Although considered feasible and cost-effective for providing diagnostics to those at-risk of HIV acquisition in difficult to reach areas (Bassett et al., 2013; Govindasamy et al., 2012; Maheswaran, Thulare, Stanistreet, Tanser, & Newell, 2012; Sharma, Ying, Tarr, & Barnabas, 2015), user acceptability of these services for AYA has yet to be evaluated.

The primary objective of this study was to evaluate the acceptability of an AYA friendly mobile SRHS that encourages health-seeking in high disease burden settings in Cape Town, South Africa. The secondary objective was to compare AYA usage and HIV outcomes at the mobile clinic versus that among AYA attending four conventional primary healthcare clinics that operate in the same health district over a similar period.

Method

Study setting and participants – The study was conducted in the Klipfontein Health Sub-structure, a high disease burden, resource limited, densely populated area in the Cape Town Metropolitan, South Africa. The mobile clinic, known as the Tutu Teen Truck (TTT, Picture(s) 2), provided an adolescent and youth-friendly wellness service where adolescents and young adults (12-24 years) could access screening for HIV, STIs, tuberculosis (TB), high blood pressure, diabetes mellitus, obesity and pregnancy. The inclusion criteria for this study limited the age of participants to 16-24 year olds for the acceptability study, and 12-24 for the comparison. The rationale for this was partly based upon the Department of Health guidelines for including minors in health research. The guidelines state that minors 16-17 years may be included in minimal harm research with an ethics review committee parental waiver. Since the second aim of the study was a folder review of health records, AYA from 12-24 years were included.

Picture(s) 2: Images of the Tutu Teen Truck: Nkosiyabo Futshane, Pam Fuzile, Desmond Raka, Nosikhumbuzo Zenane

From December 2016 to April 2017, AYA between 16-24 years old visiting the Tutu Teen Truck were recruited to participate in an acceptability study through purposive, convenient sampling. The mobile clinic parked in high traffic locations, such as commuter hubs and shopping centres, and offered free

screening and testing. These locations were chosen in partnership with community representatives. Additionally, clinic records at the mobile clinic and four conventional clinics were reviewed to compare the characteristics of AYA 12-24 years. The research was approved by the Institutional Review Board (IRB) at the University of Cape Town (HREC Ref 141/2016). In consultation with the UCT IRB, a waiver of parental consent was obtained for the study on the grounds that adolescents access these services without need for parental consent, and the act of obtaining parental consent for the research could create a barrier to participation and undermine the acceptability objective.

Procedure – Participants that self-presented at the clinic were greeted by a staff member, who recorded their demographic information electronically on a tablet device and linked this information to the participant's fingerprint on biometric software. After registration, a trained healthcare worker screened and tested participants for HIV, pregnancy, hypertension, diabetes, and obesity using point-of-care diagnostics. Participants were also screened for symptoms of STIs and TB. Participants were not required to have all tests done although the whole spectrum was offered to all where appropriate, and pregnancy checks were offered to women. After completing HCT, participants were invited to join the study. Written consent was obtained from all participants prior to completing the researcher administered questionnaire, which recorded demographics, acceptability of the clinic, and HIV risk perception. The researcher explained that she was from UCT and was not part of the mobile service team. A researcher administered data collection method was chosen to ensure completion of the questionnaire and to decrease missing responses. In addition, permission was obtained from the Cape Town Department of Health to review clinic records for four conventional government clinics in the same location during the period in which the study ran. Clinics were chosen based on proximity to the area in which the mobile clinic operated.

Design – This was a cross-sectional acceptability study which compared usage statistics of a mobile clinic versus conventional clinic facilities in the same district. Since no pre-existing acceptability instrument could be obtained, an eleven-item scale was developed, which was derived from common desirable aspects of acceptable healthcare services (Strauss et al., 2015). A likert-type scale was chosen because this method of rating services has been used in healthcare acceptability research and is amenable to generating a composite score for analysis (Davis & Jiang, 2016; Joshi, Kale, Chandel, & Pal, 2015). Participants were asked to rate the eleven aspects of the mobile clinic service by answering Likert-type scale questions with ratings that ranged from 1 – 5. A score of 5 indicated greater acceptability for all items in the scale except for a question that asked whether participants feared being seen at the clinic, which was reverse scored. The sum of the individual scale items was used to generate an acceptability score (table 4). Participants were also asked to rate on a Likert-type scale

their risk of three chronic diseases, including diabetes, hypertension and HIV. All analyses were conducted using Stata 14.0 (Stata Corporation LP, College Station, TX). Results were analysed for significant associations with sample demographics. Sample characteristics included age, gender, marital status, education, employment status, whether participants had ever tested, type of dwelling and HIV status. After calculating the proportions of HIV testing diagnoses at the mobile clinic and the conventional clinics, significant differences in proportions were analysed. Bivariate regression analyses were used to identify statistically significant associations and all significant associations (p=0,05) were included in the multivariate regression model. Associations that retained significance were retained in the model.

Results

A total sample of 303 (19% male) mostly Xhosa speaking (93%) participants between the ages of 16 and 24 years (mean age 19,7) were retained in the analysis (Table 3). Most participants were unemployed (86%) and did not earn an income (83%). Half (*n*=150, 50%) of the participants lived in informal housing and most (93%) had previously tested for HIV.

	n (%)	**mean[a]**	**p^**
Total	303 (100)	4.6	
Age (*m* = 19,7)	303 (100)		0.394
Sex			0.341
Female	246 (81.2)	4.6	
Male	57 (18.8)	4.6	
Employment			0.147
Unemployed	259 (85.5)	4.6	
Employed	44 (14.5)	4.5	
Income			0.014**
Income	53 (17.5)	4.5	
No Income	250 (82.5)	4.6	
Education			0.007**
Primary School	3 (1)	4.4	
High School	230 (75.9)	4.6	
College/ University	70 (23.1)	4.7	
Dwelling type			0.590
Formal housing	153 (50.5)	4.6	
Informal housing	150 (49.5)	4.6	
Marital Status			0.515
Single	287 (94.7)	4.6	
Cohabiting	13 (4.3)	4.7	

Married	3 (1)	4.6	
Ever Tested			0.001**
Never Tested	22 (7.3)	4.4	
Tested Before	281 (92.7)	4.6	
HIV Status			0.345
HIV positive (new diagnosis)	8 (3.3)	4.7	
HIV negative	232 (96.7)	4.6	

ªMean Acceptability scores

^Bivariate regression for Acceptability

** p <0.01

Table 3: Participant demographics and bivariate regressions for acceptability of the mobile clinic

When asked if they had used healthcare services in the past, most participants reported that they had used hospital services (47%), followed by clinics (31%) and mobile clinics (22%). No adverse experiences were reported on the mobile clinic.

	n	Median	(IQR)
Acceptability	304	4.6	(4.3-5)
1. How easy was it to understand the counselling at the mobile clinic?	304	4	(4-5)
2. Please rate how helpful was the mobile clinic service?	304	4	(4-5)
3. Would you consider using the mobile clinic service again?	304	4	(4-5)
4. How likely are you to tell others about the mobile clinic service?	304	5	(5-5)
5. How happy were you with the time it took to be seen at the mobile clinic?	304	4	(4-5)
6. Please rate how friendly was the clinic service?	304	5	(5-5)
7. How do mobile clinics compare with traditional clinics/ hospitals?	304	4	(4-5)
8. How do mobile clinics staff compare with traditional clinics/ hospitals?	304	4	(4-5)
9. How concerned are you that someone may see you at the mobile clinic? (reverse scored)	304	5	(5-5)
10. Compared with traditional clinics, mobile clinics are 1 = much worse, 5 = much better	304	4	(4-5)
11. Overall, how would you rate your experience at the mobile clinic?	304	4	(4-5)

Table 4: Acceptability ratings

Since this was a newly created instrument for measuring acceptability, a Cronbach's alpha test of reliability was conducted and indicated acceptable internal consistency (α=0,77). All surveyed participants were either happy, or very happy with the duration of the mobile clinic visit (Table 4). Almost all participants (99%, n=301) stated that the mobile clinic staff were friendly or very friendly. When asked if they would tell others about the mobile clinic service, nearly all (99%, n=302) stated

that they would. Most participants (96%, n=290) stated that they believed the service was confidential and (92%, n=279) were not concerned that someone they knew would see them at the service. All except one (99%, n=302) stated they would reuse the service. Most participants (90%, n=273) stated that the mobile service was better or much better than conventional services, while a minority (10%, n=29) stated that services at mobiles and conventional clinics were the same. A single participant (0.3%) stated that conventional clinic services were better or much better. The length of time it took to be seen at a conventional clinic facility was the most often cited (47%, n=143) barrier to accessing healthcare, followed by unfriendly staff (31%, n=93) and distance (22%, n=67). When asked to rate their risk of diabetes, hypertension and HIV infection on a Likert-type scale, 65%, 67% and 76% of participants stated that they were not at risk of these conditions respectively. A Wilcoxon signed-rank test showed that risk for HIV was rated significantly lower than either risk for diabetes (Z=-2.898, p=0.004) or hypertension (Z=-3.165, p=0.002).

In the multivariate analysis (Table 5), higher income (*p*=0.004, CI -.266 -.052), higher education (*p*=0.003, CI .022 .108) and having been previously tested for HIV (*p*=0.008, CI .053 .360) remained associated with higher acceptability scores, but there was low predictive value for the effect on acceptability (R-squared = 0.079).

Determinants of Acceptability

Usability R2 = 0,079	**Estimate**	**SE**	**t**	**p**	**95% CI**
Income	-0,16	0,054	-2,92	0,004	(-0,27; -0,05)
Education	0,06	0,022	2,98	0,003	(0,02; 0,11)
Ever tested	0,21	0,078	2,65	0,008	(0,05; 0,36)
Constant co-efficient	4,19	0,099	42,22	0,000	(4,00; 4,39)

Table 5: Multivariate regression model for acceptability

Because utilization of the mobile clinic was voluntary, the characteristics of the AYA who attended the Tutu Teen Truck was compared with all the AYA who attended the four nearest conventional clinic facilities in the area over the same period as a measure of usage. Between December 2016 and April 2017, 4887 patients (Table 6) between the ages of 12 and 25 visited SHS at the clinic facilities (3737 visited the four conventional clinics, and 1150 visited the adolescent-friendly mobile clinic). The mean age for patients in this age group was 19,1 years (19,3 years at the conventional clinic, 18,4 years at the mobile clinic).

	Total		Conventional		Mobile		
	n	%	n	%	n	%	p
Overall	4887	100	3737	76,5	1150	23,5	
Age							0,000**
Mean	19,1		19,3		18,4		
Median	19		19		17,9		
12-14	507	10,4	341	9,1	166	14,4	
15-16	680	13,9	439	11,8	241	21	
17-19	991	20,3	699	18,7	292	25,4	
20-25	2709	55,4	2258	60,4	451	39,2	
Sex							0,000**
Female	4090	83,7	3244	86,8	846	73,6	
12-14	397	9,7	289	8,9	108	12,8	
15-16	597	14,6	414	12,8	183	21,6	
17-19	862	21,1	645	19,9	217	25,7	
20-25	2234	54,6	1896	58,4	338	40	
Male	797	16,3	493	13,2	304	26,43	
12-14	110	13,8	52	10,5	58	19,1	
15-16	83	10,4	25	5,1	58	19,1	
17-19	129	16,2	54	11	75	24,7	
20-25	475	59,6	362	73,4	113	37,2	
HIV test result							0,000**
HIV+	119	2,4	73	2	46	4	
12-14	1	0,2	1	0,3	0	0	
15-16	6	0,9	1	0,2	5	2,1	
17-19	16	1,6	6	0,9	10	3,4	
20-25	96	3,5	65	2,9	31	6,9	
Female HIV+	103	2,5	64	2	39	4,6	0,000**
12-14	1	0,3	1	0,3	0	0	
15-16	5	0,8	1	0,2	4	2,2	
17-19	14	1,6	5	0,8	9	4,1	
20-25	83	3,7	57	3	26	7,7	
Male HIV+	16	2	9	1,8	7	2,3	0,642
12-14	0	0	0	0	0	0	
15-16	1	1,2	0	0	1	1,7	
17-19	2	1,6	1	1,9	1	1,3	
20-25	13	2,7	8	2,2	5	4,4	
Pregnancy tests	654		496		158		0,000**
Pregnant	167	25,5	156	31,5	11	7	

Table 6: Analysis by site with age, gender, HIV result and pregnancy result

Sixteen percent (16,3%) of patients were male, with the mobile clinic recording a higher proportion of males (26,4%) than the conventional clinics (13,2%). The overall HIV prevalence was 2,4%, where prevalence was 2% at the conventional clinics, and 4% at the mobile clinic. The HIV prevalence in the ≥20 year old age group was more than double that of the 17-19 year old group. The univariate analysis showed that patients who visited the mobile clinic differed significantly by age, sex, HIV result and pregnancy status. When HIV test result was disaggregated by age, males at the mobile were not more or less likely to be HIV positive, while females were more likely to test HIV positive at the mobile. At the mobile clinic a quarter (25,7%) of patients reported that this was their first HIV tests (this data is not recorded in the conventional clinic records).

Discussion

Mobile services offer acceptable, accessible and cost-effective youth tailored services and can provide a gateway into HIV prevention and treatment for adolescents (Bekker et al., 2015). The results here echo other studies indicating widespread acceptability and uptake of mobile health services in underserved populations (Sharma et al., 2015; van Rooyen et al., 2013). Acceptability was universally high in the sample, with the mobile clinic being perceived as efficient, confidential, friendly, easy to access, with information that was easy to understand. These results correspond with the participants responses in Chapter two. Even though almost all (96%) participants rated the mobile service as confidential, a small number (7%) were concerned that they might be seen at the clinic. Confidentiality and privacy are high priorities and it was exceptional that such a visible clinic was perceived to be confidential and private and that all participants except one were likely or very likely to tell others about the mobile. Such a finding is counterintuitive, but indicates that participants were comfortable accessing the mobile clinic in public spaces.

When the data from the two clinic types were compared, the results showed that the mean age was lower for those accessing the mobile clinic and that the mobile attracted a higher proportion of young men than the conventional clinics. This is an encouraging finding since men generally access conventional facilities at lower rates and are less likely to test and know their status than women. Consequently, mobile clinics may provide opportunities for prevention and treatment to reduce morbidity and mortality amongst young men. Moreover, the mobile clinic found a higher yield of HIV infected young people than the conventional clinics. When disaggregated by sex, HIV prevalence remained significantly higher for women visiting the mobile clinic versus the conventional clinic, but not for men. This may be due to the national trend for a delayed upswing in HIV prevalence for men when compared with women (HSRC, 2018). The pregnancy rates between the two facility types also differed significantly where more young women tested positive for pregnancy at the conventional

facilities. This may be an indication that mobiles could be effective sites for implementing convenient family planning counselling and for dispensing contraceptive methods for young people.

It was significant that previously tested participants gave higher ratings of the mobile clinic service. Qualitative data from Chapter two, which investigated young people's preferences for desirable healthcare services, showed that trust between young people and healthcare providers is vital in supporting youth engagement in care (Smith et al., 2018). It may be that those who had previously tested had a comparator and had subsequently formed good impressions of the professional-patient relationships with health providers on the mobile service, and as a result rated the service more highly. Even though debut testers gave lower ratings than repeat testers, their ratings were still high.

Overall, these results resonate with findings from elsewhere in South Africa showing that mobile clinics are an effective strategy for overcoming the barriers to reaching young people, and as an added benefit, are effective at reaching young men who access conventional clinics at lower rates than women (van Rooyen et al., 2013). The need for continued awareness raising, community-based efforts for HIV testing and case-finding of young people living with HIV is supported by the finding that participants were more likely to deny vulnerability to HIV than other chronic conditions.

Self-selection for the service and the study was a limitation that may have influenced the high levels of acceptability. Even though the mobile service strategically selects high disease burden communities, patients who know they are high risk, or who know they are infected may avoid diagnostic services because of anticipated stigma around an HIV positive result, denial, or a desire to delay knowing that they are infected. Fine-grained geospatial mapping may help to target areas as specific as streets and blocks to improve the yield of those who are most at risk. Further to this limitation is that questionnaires were researcher-led, and therefore possibly subject to social desirability bias. One way to control for this may be to use computer-assisted or tablet-based self-administered surveys, or community-based surveys away from clinic settings to minimise this bias. Even so, while self-selection may have positively skewed acceptability, the comparison with the conventional clinics showed that the mobile clinic saw proportionately more HIV positive patients, indicating that mobile clinics may be more successful at finding new HIV infections.

The study did not record participation refusals and associated reasons for refusal. The majority (68%) of those who completed the questionnaire were female, and therefore an equal spread of answers across the sexes was not established. However, even though young men only constituted 32% of those who completed the questionnaire, this figure was higher than the proportion of men who visited the mobile clinic during the course of the study (26%). Since inception in 2015, men have constituted 40%

of clinic visits at the mobile, which is encouraging. While the higher proportion of young men testing at the mobile may indicate that mobile testing is more desirable to men than testing at a conventional facility, the proportion of those infected was not significantly different from the conventional clinic. Future research could investigate mobile clinics that incorporate young men's healthcare needs since dedicated men's clinics may be a more attractive option because they are tailored to men. Since men are harder to reach (Cornell, Cox, & Wilkinson, 2015), the same behavioural economics principles would apply to improving uptake of SHS.

Mobile clinics can offer convenient and complimentary service to conventional clinics and the ability to actively target at-risk communities can provide earlier detection of HIV and provide relief to brick and mortar clinics. Additionally, mobile SHS can provide environmental ease (system 1), making health-seeking more convenient for AYA. Examples of possible models for mobile units include diagnostic versus one-stop mobile clinics that provide a range of diagnostic, prevention and treatment services. Cost effectiveness of an integrated, one-stop diagnostic and prevention and treatment service should be determined, but may go some way towards addressing attrition between testing and treatment services (Siegler et al., 2018).

This study implemented the recommendation from Chapter two into a SHS platform. These results show that the mobile service platform was an outstanding system 1 approach (Chapter one, figure 1) to providing SHS. Mobile clinics can target high risk communities and can provide convenient access to much needed SHS. This delivery platform responds directly to the desires expressed by adolescents in Chapter two and leans heavily into decreasing effort, decreasing time, improving the emotional experience, and ensuring that uptake is more automatic by strategically locating the service where it is needed.

Providing the nudge (libertarian paternalism) through this environmental change was associated with higher rates of HIV diagnosis compared with the conventional clinic. This study demonstrates that mobile clinics are more desirable and can achieve high acceptability amongst young people in need of sexual and reproductive healthcare in a resource-limited, high disease burden setting in South Africa. The results further demonstrated that this mobile clinic offered convenience, trusting relationship and confidentiality. Accordingly, mobile clinics should be used as part of a multi-faceted approach to increase the convenience of HIV testing and counselling for adolescents and young adults in resource-limited settings. Future studies to evaluate acceptability of these services amongst those even harder to reach, including young men and boys and debut testers are warranted.

Chapter four: HIV self-testing in youth-friendly clinic settings is convenient, has high usability, can be used accurately, and is preferred over conventional testing experiences

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Abstract

Introduction: Since HIV testing in South African adolescents and young adults is sub-optimal, the objective of the current study was to investigate the feasibility and acceptability of an HIV rapid self-testing device in adolescents and young people at the Desmond Tutu HIV Foundation Youth Centre and Mobile Clinic.

Methods: Self-presenting adolescents and young adults were invited to participate in a study investigating the fidelity, usability and acceptability of the AtomoRapid HIV Rapid self-testing device. Trained healthcare workers trained participants to use the device before the participant conducted the HIV self-test with device usage instructions. The healthcare worker then conducted a questionnaire-based survey to assess outcomes.

Results: Of the 224 enrolled participants between 16 and 24 years of age, 155 (69,2%) were female. Overall, fidelity was high; 216 (96,4%) participants correctly completed the test and correctly read and interpreted the HIV test result. There were eight (3,6%) user errors overall; six participants failed to prick their finger even though the lancet fired correctly. There were two user errors where participants failed to use the capillary tube correctly. Participants rated acceptability and usability highly, with debut testers giving significantly higher ratings for both. Younger participants gave significantly higher ratings of acceptability.

Discussion: Adolescents and young adults found HIV self-testing highly acceptable with the AtomoRapid and they used the device accurately. Further research should investigate how, where and when to deploy HIV self-testing as a means to accompany existing strategies in reaching the UNAIDS goal to test 90% of all individuals worldwide.

Introduction

Access to regular HIV testing and knowledge of one's status is the gateway to HIV prevention and treatment and thus a public health imperative (Mavedzenge et al., 2013; Walensky & Bassett, 2011). The UNAIDS launch of the 90-90-90 campaign has set an ambitious goal of testing 90% of people living with HIV worldwide by 2020 (UNAIDS, 2014). This is in an effort to ensure all those who are positive are offered lifesaving antiretroviral therapy. What is more, knowledge of HIV status has been associated with a reduction in sexual risk behaviour and improved linkage to HIV care and treatment services (Attia, Egger, Müller, Zwahlen, & Low, 2009; Bunnell et al., 2006; Marks, Crepaz, Senterfitt, & Janssen, 2005).

Until recently, HIV counselling and testing (HCT) has been accessible from primary healthcare facilities such as clinics and day hospitals. However, the majority of adolescents and young people living in Sub-Saharan Africa have not tested and do not know their HIV status (Johnson, Rehle, Jooste, & Bekker, 2015; WHO, 2013). Even though most (85%) South Africans who had tested HIV positive were aware of their HIV status, this figure was well below the 90-90-90 target in youth 15-24 years (24% in males and 65% females) (HSRC, 2018). Adolescents do not or cannot access healthcare services including HIV testing due to perceived or actual barriers of accessibility, overburdened health systems, lack of confidentiality, and stigma (Bateganya, Abdulwadud, & Kiene, 2010; Dickson et al., 2007; Spielberg, Levine, & Weaver, 2003; Wood & Jewkes, 2006). Locating HIV testing services outside of traditional health facilities may provide more accessible, convenient and less stigmatizing opportunities for young people to test. Community-based testing, including mobile testing, home testing and self-administered tests may further facilitate testing in the home or other more acceptable venues and contribute towards the first 90 of the 90-90-90 goals.

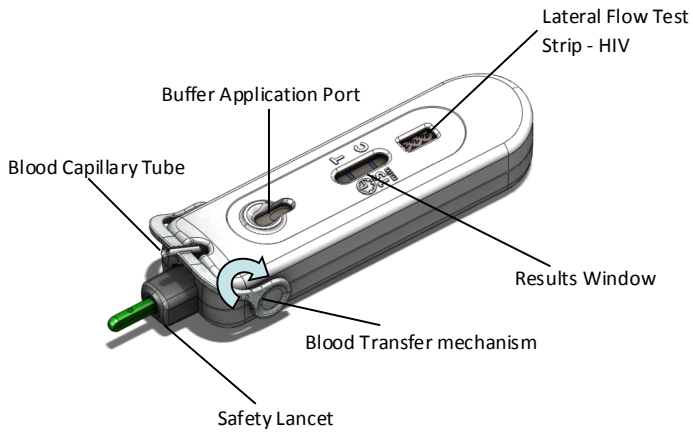
Commercially, there are a plethora of "gold standard" lateral flow (LF) blood test kits and oral/ buccal mucosal "rapid" tests which test for HIV antibodies giving an almost immediate, point of care diagnosis of HIV infection. Traditionally these have been administered by trained healthcare workers or counsellors. Self-testing kits are similarly designed, but come with detailed user instructions so that an individual may 1) collect his or her own blood specimen/buccal fluid specimen 2) perform a simple rapid HIV test and 3) interpret the result in private (Lee et al., 2007; Volk et al., 2015). The HIV self-testing device that tests buccal fluid and is known as OraQuick has been found to be highly acceptable by adult and high risk groups (Choko et al., 2015; Choko et al., 2011). While most research in HIV self-testing has been conducted with buccal fluid, one study investigated the use of a blood based HIV test (Abbott Determine 1/2) and recommended deferring self-testing with the device due to a failure in

compliance in one or more steps and the high rates (12%) of test result misinterpretation (Lee et al., 2007).

Although saliva-based HIV testing may be easier for self-testing and does not involve universal precautions, the sensitivity of oral/ buccal mucosal testing is lower than blood based testing (Pai et al., 2012). The lowest for saliva-based testing indicates 91% (WHO & UNITAID, 2017), and even though oral/ buccal mucosal self-testing has lower sensitivity than blood-based tests, this is an acceptable level of sensitivity. While blood-based assays are less expensive, more available and considered the norm, in order for blood sample self-administered tests to be safe, acceptable, and widely used, ease-of-use, fidelity and reliability will be critical factors to be assessed. Atomo Diagnostics Pty Ltd. has developed an "all-in-one" LF blood test device known as the AtomoRapid™ Professional Device. This test differs from traditional HIV tests because the lancet, the capillary blood collection tube, and the test strip are all contained in one device. The objective of the study was to investigate usability, acceptability and fidelity of the AtomoRapid device as an HIV self-test among adolescents and young people in high HIV burden communities in Cape Town, South Africa.

Methods

The HIV testing device under examination in this study was the AtomoRapid Professional Version 1 HIV Assay MRLF (Part # MRLF-A-10, revision B) device known as AtomoRapid. The AtomoRapid device uses the Advanced Quality Rapid Anti-HIV (1&2) test. The Elisa and Western Blot reference tests indicated 100% specificity for 150 confirmed negative samples, and 100% sensitivity for 150 confirmed positive samples (Kagulire et al., 2011). The diagnostic performance of the device has been shown by the South African National Institute for Communicable Diseases and communicated via email after testing in standard clinic environments following standard procedures and techniques for LF blood testing (P. Dabula, [patience.dabula@nhls.ac.za], letter, 10 July, 2013). As shown in Figure 2 and



Picture(s) 2, the device contains an automatically retracting safety lancet, a blood collection capillary tube that flips over to deposit a blood sample onto the lateral flow test strip with its result indicator all in one self-contained device.

Figure 2: AtomoRapid device

Participants – A convenience sample of self-presenting adolescents and young adults between the ages of 16 and 25 years, routinely attending the Desmond Tutu Youth Centre Clinic (DTYC) and the Desmond Tutu HIV Foundation's Tutu Tester Mobile clinic, were recruited into the study over a six-month period between May and October 2014. The participants differed from the normal clinic population in that people between 16 and 25 were recruited because they are at increased risk of HIV infection and they are less likely to test for HIV at a traditional clinic facility. These community-based services provide healthcare in under-resourced communities and have both been described elsewhere (Black et al., 2014; van Schaik et al., 2010). Point of care HIV testing is offered free of charge as part of the service package in both settings. Participants who were willing to provide informed consent for the HIV self-test and participate in the research study were included. The study was reviewed and approved by the University of Cape Town Health Science Research Ethics Committee. HIV testing does not require parental consent over the age of 12 years in South Africa. On these grounds parental consent was waived by the Ethics Committee for participants aged 16 and 17 years old. Appropriate counselling, care and referral support was offered to all testers on the Tutu Tester mobile services and at the DTHF Youth Centre clinic.

Picture(s) 3: Pictures of HIVST

Procedure – Participants were met by a trained and experienced healthcare practitioner (HCP), an HCT counsellor or nurse. After informed consent procedures, the participants were trained to use the AtomoRapid device. The training session included an explanation and a demonstration of the device and included study participants reviewing the pictorial Instructions For Use (IFU) contained in the device packaging. This training took on average five minutes and was conducted by a counsellor. Participants then completed an HIV self-test with the AtomoRapid device under the supervision of, but without assistance from the HCP. If the participant asked for assistance, the HCP asked the participant to continue until the test was completed. The steps of use for the device included the

following: Participants selected and wiped a finger with an alcohol swab, they then released the sterility tab on the lancet and applied the lancet pad to their finger and the lancet was triggered by applied pressure. They were then required to milk a blood bubble on the finger pad and allow collection of a 50uL sample into the capillary tube. The tube was then flipped over onto the test strip. Participants were required to apply buffer solution to the strip and wait 15 minutes before reading and interpreting the test result. The HCP then interviewed the participant using a questionnaire rating the usability and acceptability of the device. After completing the questionnaire, participants answered questions about their demographics.

Outcome measures – The questionnaire administered by the HCP assessed usability and acceptability of the device on a likert type scale with ratings ranging from 1-5 on both continuous variables. Usability was defined as the ease of using the device and was operationalised by asking participants to rate the ease-of-use of the device on eight domains. Acceptability was defined as preference for using the device and was operationalised by asking participants to rate their preference for self-testing. A score of 5 indicated a better rating in all cases except for the question that asked whether the participant would self-test again with this device (5 indicated very unlikely). The scale was designed to measure the ease-of-use of each step of using the device. The subscales for usability were combined to create a composite score for usability (Davis & Jiang, 2016; Joshi et al., 2015). The same process was followed to create an acceptability score. The HCP recorded any process errors relating to the steps of use. The total number and types of errors, including result interpretation, were recorded. Each step was recorded as correctly or incorrectly completed.

As per clinic standard operating procedure, participants who tested HIV negative received risk reduction counselling. Participants who tested HIV positive were referred to the clinic nurse for assessment for treatment, including a rapid CD4 count. Newly diagnosed individuals were referred with a comprehensive nurse's letter to their preferred clinic facility for ongoing treatment.

Analysis – Statistical analyses were conducted using version STATA 14 (Stata Corporation, College Station, TX) at the 5% level of significance. The study was descriptive and exploratory, making use of inferential statistics. There were no a priori hypotheses. Demographics were entered as categorical variables. The F test, X^2 and Fisher exact tests were used to analyse outcomes for categorical variables. Bivariate and multivariate regression was used to identify factors independently associated with usability, acceptability and fidelity. Statistically significant factors at $p \leq 0.05$ in the bivariate analysis were entered into a multivariable analysis. Subsequently, a stepwise approach was used to explore interactions between factors associated with outcome variables.

Results

Of the 225 participants, between the ages of 16 and 25 years (mean age 19) 224 were retained in the analysis and 69.2% were female (Table 7), which was representative of the gender split over the course of the study. One participant was excluded since no data was recorded for the participant. The sample consisted of predominantly Xhosa speaking South Africans who lived in brick and mortar housing, or formal accommodation (*n*=141, 63.8%), with the remaining participants living in shanty houses. There were 45 (20.1%) participants who reported no prior HIV test and therefore the AtomoRapid self-test was their first experience of HIV testing.

	n (%)	mean[a]	p*	n	mean†	pΔ
Total	224 (100)	4.2		222	4.0	
Age (*m* = 19,42)	224		0.002			0.641
Sex			0.499			0.028
Female	155 (69.20)	4.2		153	3.9	
Male	69 (30.80)	4.1		69	4.1	
Employment			0.301			0.049
Unemployed	206 (91.96)	4.2		204	3.9	
Employed	18 (8.04)	4.0		18	4.2	
Income			0.056			0.292
Income	25 (11.16)	3.9		25	4.1	
No Income	199 (88.84)	4.2		197	4.0	
Education			0.137			0.010
Primary School	13 (5.86)	3.8		13	3.8	
High School	193 (86.94)	4.2		192	4.0	
College/ University	16 (7.21)	4.2		15	4.2	
Dwelling type			0.327			0.000
Formal housing	141 (63.80)	4.2		139	4.1	
Informal housing	80 (36.20)	4.1		80	3.8	
Marital Status			0.110			0.270
Single	218 (97.76)	4.2		216	4.0	
Cohabiting	1 (0.45)	4.0		1	3.4	
Married	4 (1.79)	3.6		4	4.3	
Ever Tested			0.000			0.000
Never Tested	45 (20.09)	4.5		45	4.2	
Tested Before	179 (79.91)	4.1		177	3.9	

[a]Mean Acceptability scores

*Bivariate regression for Acceptability

†Mean Usability scores

ΔBivariate regression for Usability

Not all columns total to 224 due to missing data

Table 7: Participant demographics and bivariate regressions for acceptability and usability

Fidelity – All but eight (3.6%) participants correctly completed, read and interpreted their test result. Out of the eight, there was one user error (Table 8) where a participant failed to fill the capillary tube sufficiently. There was a single device failure where the blood transfer mechanism broke while the participant flipped the capillary tube over to the test strip. Additionally, in six instances the participant failed to correctly pierce their finger with the lancet, although the device lancet had fired correctly. When the test was repeated all eight participants used the device correctly.

Type of error
6 Difficulties firing / activating the safety lancet (with one hand)
1 Difficulties in blood Collection
1 Adequacy of collected blood volume (tube over / under filled)

Table 8: User device errors

Usability – Overall, the mean score for the usability (or ease-of-use) of the device was 4 (median 3.9) out of a maximum rating of 5 (Table 9) where 47% of participants scored usability 4 or higher. Six out of eight subscales of usability were rated above 4, with the exception of lancet use (3.7) and

	n	**Median**	**(IQR)**
Usability (5 = highest rating)	222	3.9	(3,7-4,4)
1. How easy was it to understand the device training?	220	4	(4-5)
2. How easy was it to understand the device instructions for use?	221	4	(4-5)
3. How comfortable was it to use the device?	221	4	(4-5)
4. How easy was it to activate the lancet with one hand?	222	4	(3-5)
5. How easy was it to identify when the blood collection tube was full?	222	4	(4-5)
6. How easy was it to apply the buffer solution?	220	4	(4-5)
7. How easy was it to read the test result?	220	4	(4-5)
8. How easy was it to interpret the T and C markers on the device?	220	4	(4-5)
Acceptability	221	4.3	(3,7-5)
1. Preference for self-testing (5 = high preference)	219	4	(3-5)
2. Put off self-testing (5 = not put off)	221	4	(3-5)
3. Likelihood of telling others about HIV self-testing	217	5	(4-5)

Not all columns total to 224 due to missing data

Table 9: Usability and acceptability rating

Acceptability – Participants mean acceptability of the device was 4.18 out of 5 (median 4.3). Participants generally reported preference for self-testing (74,89%) over traditional HCT, and 72,5% of participants reported that they had not been put off of self-testing. Most participants stated that they would tell others about self-testing (89,86%).

There were 19 participants who stated that they had had a bad experience with self-testing. Most participants (*n*=12) who reported a bad experience said that they found it distressing to prick themselves. Six participants stated that they disliked testing themselves, while one participant did not give a reason. There were no reports of bad experience among the 45 participants who had not previously tested for HIV.

In a multivariate linear regression model (Table 10), dwelling type, education level and whether the participant had ever tested for HIV were significantly associated with usability. There was a small, but significant difference between those living in formal dwellings and those in informal dwellings in terms of their average usability scores (0.15 p = 0.02). Those with higher education levels gave higher usability ratings and with every unit increase in education, usability increased by 0,10 (p = 0.005). Debut testers gave higher usability ratings for the device, where the average difference between those who had previously tested and debut testers was -0,30 (p = 0.000). Age, marital status, employment and income had no significant effect on usability. Males rated both the usability of the instructions and the ease of reading the test result higher than females

Determinants of Usability			
Usability R2 = 0.15	Estimate	95% CI	*p* value
Ever tested	-0.30	(-0.45, -0.15)	0.000
Education	0.10	(0.03, 0.18)	0.005
Dwelling type	0.17	(0.04, 0.30)	0.009
Constant co-efficient	3.75	(3.48, 4.02)	0.000
Determinants of Acceptability			
Acceptability R2 = 0.08	Estimate	95% CI	*p* value
Ever Tested	-0.36	(-0.62, -0.12)	0.004
Age	-0.05	(-0.10, -0.01)	0.026
Constant co-efficient	5.46	(4.61, 6.31)	0.000
Usability Determinants of Acceptability			
Usability R2 = 0.10	Estimate	95% CI	*p* value
Lancet use	0.16	(0.07, 0.24)	0.012
Buffer use	0.17	(0.04, 0.30)	0.000
Constant co-efficient	2.89	(2.32, 3.47)	0.000

Table 10: Multivariate regression models for acceptability and usability

In the multivariate regression model, age and whether the participants had previously tested were significantly associated with acceptability (Table 10). Younger participants were more likely to give higher acceptability ratings and each year increase in age was associated with a 0,05 (p = 0.026) reduction in acceptability. Similarly, debut testers gave higher acceptability ratings where the average

difference between those who had previously tested and debut testers was 0,36 (p = 0.004). No other demographic variables had a significant association with acceptability.

Acceptability and usability scale items – Results confirmed that acceptability was significantly associated with good ratings of lancet use and buffer use (Table 10). Higher usability ratings for the finger prick lancet were associated with higher acceptability scores. In the multivariate regression model for the effect of items in the usability scale, these items were closely associated: for every unit increase in lancet usability, acceptability increased by 0.16 (p = 0.012). With every unit increase for the usability of the buffer solution, acceptability increased by 0.17 (p = 0.000).

Discussion

This study confirms that HIV self-testing is highly acceptable to adolescents accessing community-based testing services. This is consistent with results from older adult populations and high-risk groups (Choko et al., 2011; Volk et al., 2015). Every test result (including the 8 repeated tests) was read and interpreted correctly, showing that self-testing can be successfully used, read and interpreted by an adolescent population.

There were six instances in which the supervising healthcare worker reported that the participants did not correctly pierce their finger. These participants were reticent about pricking their own finger, did not fire the needle correctly and therefore failed to draw blood. This suggests that those who are anxious about pricking themselves may not correctly complete the finger prick and consequently may struggle to draw blood. The lancet in the AtomoRapid device retracts into the device after firing, and therefore a new device must be used if the finger prick fails. Those who failed to use the device correctly, cited lancet use as a barrier to acceptability of self-testing. Despite this, all six participants who failed on the first attempt used the lancet successfully when given a second attempt. To account for the possibility of patients failing to prick themselves, it may be useful to include an extra lancet in the package. Participants who experience ongoing difficulty in self-pricking may find other options, such as oral/ buccal mucosal self-testing more acceptable.

Overall, this device and self-testing was acceptable to adolescents and young adults. Debut and younger testers rated the device more acceptable than their peers. This may be related to younger testers not having preconceived ideas about testing and the novelty of the experience may have increased enthusiasm. Conversely, those who were older and/or HIV test experienced may have had preconceived expectations different from the self-testing experience, which might have led to slightly less favourable, although by no means unfavourable, ratings of acceptability. In addition, those in

formal housing and those with higher education rated usability higher. Despite this we did not find an association between dwelling type and education. It is possible that individuals living in formal dwellings may be more exposed to other sorts of technology.

There were a number of limitations in this study that may impact generalising the results. The study was run in two settings at youth friendly services, and those who attended identified as isiXhosa speaking. While the present study demonstrated that young people can self-test with the AtomoRapid, this study did not explore the environment in which self-testing can be safely undertaken by adolescents. In this case, the testing was done in a supportive environment where health care professionals were on hand to provide support and counselling. The safe deployment of devices to individuals to enable testing in private should be further explored. The results of this study demonstrate that self-testing may encourage earlier case-finding in the adolescent population, with the possible benefit of reducing infections (Maheswaran et al., 2016).

Adolescents in South Africa are a vulnerable population at significant risk of HIV acquisition. HIV testing is a key component of adolescent healthcare in this region and early detection and treatment of HIV prolongs life and reduces infectiousness. Inadequate testing rates show there is still room for innovation in this population. Self-testing is a novel means to make testing more accessible, confidential and available at non-traditional venues such as pharmacies and community venues as well as in the home. As PrEP has been approved for use in South Africa, HIV self-testing with an easy to use kit would be valuable in supporting self-monitoring. However, LF blood based testing with the AtomoRapid device is not currently widely available in South Africa. While not presently commercially available, consideration of the cost is pivotal in driving HIV self-testing. This study confirms that HIV self-testing with the AtomoRapid device can be used with a high degree of fidelity and acceptability by South African adolescents and youth. Further research will define how much additional support an adolescent may require when self-testing and in which environments this could be undertaken safely. Whilst disclosure, post-test support and linkage to HIV services remain barriers to the HIV care continuum, mechanisms such as self-testing may assist in realizing the first 90 of 90-90-90.

As recommended by the behavioural economics model, options that lean towards system 1 thinking (Chapter 1, figure 1) are likely to increase adoption of the behaviour. Since HIVST is under one's own volition, quicker compared to more conventional testing methods, requires less effort to complete and does not require visiting a busy clinic facility, the option leans towards system 1 thinking. It is therefore advisable to use HIVST when designing options to create opportunities for young people to test on their own and/ or at their own convenience, outside of conventional testing methods.

Chapter five: Young male's uptake and acceptability of Medical Male Circumcision in two culturally distinct settings in South Africa: A prevention intervention examining the impact of cultural context on circumcision uptake

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Abstract

Introduction: Young South Africans incur HIV infection due to sexual behaviours in the midst of endemic HIV. While nationally scaled medical male circumcision (MMC) can help curb HIV infection rates in countries such as South Africa, MMC uptake has not been consistent or universal, suggesting variable acceptability among men. Both MMC and traditional circumcision (TMC) are practised in South Africa. For male circumcision to be most effective for HIV prevention, it should be performed prior to sexual debut with complete removal of the foreskin. The MACHO study investigated uptake and preference for MMC versus TMC in two culturally distinct settings in South Africa.

Methods: This observational, longitudinal, cohort study, investigated circumcision preferences and uptake in 100 males (14-17 years) and their guardians in Cape Town and Soweto. Data were collected via researcher administered surveys and participants were followed up every 4 months over a 24 month period.

Results: 100 adolescent boys (Cape Town n=50, Soweto n=50; mean age 15, IQR 14-16) and their guardians were enrolled. At baseline 42 (84%) boys from Soweto (0/50 from Cape Town) preferred MMC over TMC prior to circumcision. Sowetan participants were more likely to elect circumcision (TMC=1(2%), MMC=11(22%)) than those from Cape Town (TMC=1(2%)) over 13.6 months of follow-up (HR 18.9, 95% CI 2.37-150.71, p= 0.006).

Discussion: MMC was the preferred option for young men in Soweto compared with those in Cape Town and this translated into practise. Despite knowledge about the benefits of early MMC, many participants delayed uptake, potentially reducing the MMC benefits before sexual debut. Programs promoting circumcision should consider the influence of local practices and in order to realise full HIV prevention benefits, efforts should be made to ensure all circumcision is safe, prior to sexual debut, and contextually responsive.

Introduction

Estimates suggest that 36% of all heterosexual transmission of HIV in South Africa occurs in the 15-24 age group (Johnson et al., 2009). While HIV counselling and testing is on the increase in young South Africans (Maughan-Brown, Lloyd, Bor, & Venkataramani, 2015, 2016), men use diagnostic and prevention services less and are less likely to be in HIV care than women (Dovel, Yeatman, Watkins, & Poulin, 2015). Consequently, men have higher levels of HIV-related mortality than women.

Male medical circumcision (MMC), defined as a complete surgical removal of the foreskin, was found to reduce HIV infection in heterosexual men (Siegfried, Muller, Deeks, & Volmink, 2009) by 60% in South Africa and Kenya (Auvert et al., 2005; Bailey et al., 2007) and 67% in Uganda (Gray et al., 2012). The keratinization of the remaining skin, reduced skin surface area and target cells for HIV, and faster drying after sexual contact post circumcision are some of the factors thought to contribute to prevention (Auvert et al., 2005; Patterson et al., 2002). While circumcision does not offer the same protection as consistent condom or PrEP use, circumcision is a once off procedure that provides ongoing protection. This once off intervention has been shown to accrue cumulative prevention benefit over a sustained period and no additional effort is required (Gray et al., 2012). Moreover, modelling suggests that MMC may offer protection for women and significantly increase the number of infections averted (Hallett et al., 2011). Accordingly, MMC has been suggested as an efficacious prevention strategy for men in high HIV disease burden areas (Westercamp & Bailey, 2007; WHO, 2018) and is an excellent option for providing benefit for relatively little effort on the part of those who adopt it.

Both traditional male circumcision (TMC) and MMC are variably practiced across South Africa, with TMC traditionally practiced in Limpopo, Kwa-Zulu Natal, the Eastern Cape and the Western Cape provinces (SePedi, Tshivenda, Zulu and isiXhosa speaking areas) (Connolly, Simbayi, Shanmugam, & Nqeketo, 2008; Kripke et al., 2016). Since 2010, more than 60% of MMCs were conducted in males under 20 years, and 40% under the age of 15 years (Kripke et al., 2016). While the national statistics were not aggregated by age category, the Gauteng province had the second highest number (n=516,988) of MMCs after KwaZulu-Natal (n=522,920), while the Western Cape province had the third lowest number of circumcisions (n=50,261) (Kripke et al., 2016). National uptake was just below 30% in males between 15 and 24 years (Ortblad et al., 2018). Concerns have been raised that prevention effectiveness can be reduced if circumcision is partial or is performed after sexual debut (Connolly et al., 2008). While there is provision for 16 and 17 year olds to undergo circumcision with written parental or guardian permission, the legal age has been set at 18 years (Vincent, 2008). One South African study found that the mean age for circumcision was 19 years with 90% of 472 males

circumcised in late adolescence and early adulthood between the ages of 17 and 22 years (Maughan-Brown, Venkataramani, Nattrass, Seekings, & Whiteside, 2011). Another study conducted in Cape Town, South Africa, with a large isiXhosa speaking population who practice TMC, found low acceptability for MMC, around a quarter of TMCs were incomplete, and that circumcision took place at around 21 years (Mark et al., 2012). As is widely acknowledged, the study emphasized that TMC was considered a crucial rite of passage into manhood. In summary, the limited data on the acceptability of MMC promotion (Lagarde, Dirk, Puren, Reathe, & Bertran, 2003) requires further investigation to explore desirable features of an ideal HIV prevention service offering an MMC program for young men. While other studies have investigated acceptability and attitudes of South African men towards circumcision (Lagarde et al., 2003), this observational study was designed to investigate preferences for and uptake of MMC at youth friendly clinics in young South African men from different ethnicities, around the time of sexual debut.

Methods

This study was part of the CHAMPS (Choices for HIV Adolescent Methods of Prevention in South Africa) project (NIH award 1R01AI094586), which specifically focused on the needs and preferences of adolescents in HIV prevention.

Setting and participants – This study investigated the acceptability of MMC in young men (14-17 years) in two locations, Masiphumelele, Cape Town (Western Cape), and Soweto (Gauteng Province). Masiphumelele is largely isiXhosa speaking (Census 2011) and data from the Cape Area Panel Study (Maughan-Brown et al., 2011) showed that Xhosa men in Cape Town were generally circumcised at 17 years or later (Connolly et al., 2008; Mark et al., 2012; Maughan-Brown et al., 2011). Soweto is a predominantly isiZulu (37%), SeSotho (16%) and SeTswana (13%) speaking township, with large cohorts of Xitsonga (9%), isiXhosa (9%) and TshiVenda (5%) speaking people (http://www.statssa.gov.za). Participants were recruited through extensive community outreach and by using links with local MMC service providers and key stakeholders. Young males were eligible for the study if they were in good health, tested HIV negative at screening, were between the ages of 14 and 17 years, and were not circumcised. The age inclusion criteria was based upon sexual debut in South African men, which was 16,7 years in 2012 (HSRC, 2018). Overall, 50 participants and their legal guardians were enrolled at each site. In addition to providing assent for study participation, enrolment was contingent upon written consent by the parent or guardian.

Design – The MACHO Study (Male Adolescent Choices for HIV Prevention Options) was a multi-site, longitudinal mixed methods cohort study which investigated preferences for, attitudes toward, and

uptake of elective MMC in 100 males (14-17 years), their guardians and other key informants in Cape Town and Soweto. Ethical approval was obtained from the Institutional Review Boards of the University of Cape Town and University of the Witwatersrand.

Picture(s) 4: Young men attending group sessions

Participants were followed up over a 24-month period and data were collected via researcher administered surveys.

A number of issues related to circumcision were covered, including attitudes towards adolescent male circumcision, cultural influences, adolescent preferences regarding male circumcision services, whether perceived protection against HIV infection provided by male circumcision might lead to sexual disinhibition or risk compensation, condom use and practices, and other factors that could impact the decision to undergo circumcision.

Procedure – After providing informed consent and before being enrolled into the study, potential participants were screened for eligibility, underwent HIV counselling and testing, and were physically examined to determine circumcision status. Participants were requested to complete follow-up visits every four months until the end of the study (maximum of 20 months). Data were collected from May 2014 until December 2015. Using interviewer-administered questionnaires, participants were required to complete a sexual risk behaviour questionnaire, a circumcision self-report, circumcision acceptability questionnaire for those circumcised, and a social harms and adverse events assessment as well as undergoing HIV counseling and testing at all visits including enrollment. The questionnaires were piloted with the community advisory boards. Participants also attended men's health information sessions at follow-up visits, which covered a broad range of topics related to physical, emotional, and sexual wellness, and the benefits of circumcision. The content of these sessions was developed by the study team in partnership with the community advisory board. These sessions were developed to facilitate retention by building a sense of community among participants, their guardians, and the study staff. The sessions were not developed to be an intervention.

At each visit over the duration of the study, 1) acceptability of male circumcision (if performed), 2) preferences around circumcision and 3) sexual risk behaviour were recorded. Legal guardians were also asked to complete a questionnaire on preferences for circumcision (included in this Chapter) and attend focus groups on circumcision (not part of this Chapter). If at any time participants indicated a desire to undergo circumcision this was recorded. In addition, if preferred, they were referred to experienced MMC clinics where extensive information about the benefits and risks was provided.

Analysis – The results were described and bivariate analyses were conducted to identify statistically significant associations ($p \leq 0.05$) for inclusion in the multivariate analysis. Cox proportional hazards models examined the association between research site (exposure) and time to circumcision (event). Time to circumcision was measured in days and participants were followed from baseline (day of enrolment) until circumcision, lost to follow-up, or censoring (the last day of follow-up). The data were analysed in STATA 14.

Results

The study enrolled 100 adolescent boys (Cape Town *n*=50; Soweto *n*=50) (Table 11) with a mean age of 15 (IQR: 14-16) and their guardians (n=97). Most participants from the Cape Town site were isiXhosa speaking (*n*=44, 88%), while half of the participants at the Soweto site were isiZulu speaking (*n*=25, 50%).

		Cape Town n=50 (%)	Soweto n=50 (%)	Total n=100 (%)	P-value
Circumcised	MMC	0	11(22)	11(11)	0,001
	TMC	1(2)	1(2)	2(2)	
Had sex before enrolment	Yes	18(36)	9(18)	27(27)	0,043
Median (IQR) age at enrolment in years		15 (14 - 16)	15 (15 - 16)	-	-
Had sex during follow-up	Yes	37(74)	36(72)	73(73)	0,824
Median (IQR) age of sexual debut in years		15 (13,5 – 16)	15 (14 - 15,75)	-	-
	14	21(42)	12(24)	0	
	15	16(32)	18(36)	0	
	16	7(14)	12(24)	0	
	17	6(12)	8(16)	0	
In school	Yes	49(98)	50(100)	99(99)	-
Working	Yes	3(6)	0	3(3)	0,086
Race	Black	49(98)	48(96)	97(97)	0,694
	Coloured	1(2)	0	1(1)	
	Other	0	2(4)	2(2)	
Ethnicity	Xhosa	44(88)	12(24)	56(56)	< 0,001
	Zulu	1(2)	25(50)	26(26)	
	Sotho / Tswana	3(6)	9(18)	12(12)	
	Afrikaans	1(2)	0	1(1)	
	Other	1(2)	4(8)	5(5)	
Circumcision by ethnicity	Xhosa	1 TMC	1 TMC, 1MMC		
	Zulu	0	5 MMC		
	Sotho / Tswana	0	3 MMC		
	Afrikaans	0	0		
	Other	0	2 MMC		
New HIV Infection		0	0	0	-
Mean (SD) follow-up in days		492 (169)	341 (167)	-	-

Table 11: Characteristics of the Cape Town and Soweto cohorts

At baseline 27% had sexually debuted with a median age of 15 (IQR: 15-17). At the final study visit, nearly three quarters (*n*=73, 73%) of participants reported sexual activity. Prior to circumcision no boys in Cape Town preferred MMC, while in Soweto most (42 of 50) preferred MMC over TMC. Each participant had on average 417 days follow-up and in approximately two years of follow-up 13 boys underwent circumcision, one in Cape Town and twelve in Soweto. Each site accounted for one of the two TMCs, and all (11) MMCs took place in Soweto. Uptake of circumcision differed by ethnicity: 5,4%

in isiXhosa (1 TMC in Cape Town, 1 TMC and 1 MMC in Soweto), 19,2% in isiZulu (5 MMCs in Soweto) and 33,3% in SeSotho / SeTswana (3 MMCs in Soweto) people (2 MMCs in ethnicity unspecified). There were no seroconversions during study follow-up.

Knowledge/awareness – Almost all legal guardians wanted circumcision for their son and most adolescents wanted to be circumcised (Table 12). Eighty-five (87%) out of 97 participant guardians were aware that MMC protected against HIV and STI's. The ten legal guardians unaware of the protection offered by MMC were all from CT (p = 0,001). Overall, most (86%) adolescents were aware of the protection offered by MMC. Participants at Cape Town were less aware of the protection offered by MMC (p = 0,019) at baseline. At the fourth study visit, the difference between the two sites was not significant (p = 0.164). At the fourth study visit, participants' desire to be circumcised had not changed from enrolment.

		Cape Town (n = 50)	**Soweto (n = 50)**	**Total (n = 100)**	**P-value**
Legal guardian knowledge and preferences					
MMC protects against HIV	Yes	38(72)	47(94)	85(85)	0,001
Want circumcision	Yes	50(100)	46(92)	95(95)	0,305
Preference	MMC	11(22)	42(84)	53(53)	<0,001
Concerns TMC	Yes	32(64)	42(84)	74(74)	0,01
Concerns MMC	Yes	28(56)	1(1)	29(29)	<0,001
Adolescent knowledge and preferences					
MMC protects against HIV	Yes	38(76)	48(96)	86(86)	0,019
Want circumcision	Yes	45(90)	47(94)	92(92)	0,156
Preference	MMC	0	42(84)	42(42)	<0,001
Concerns TMC	Yes	13(26)	43(86)	56(56)	<0,001
Concerns MMC	Yes	22(44)	3(6)	25(25)	<0,001

Table 12: Preferences for circumcision

Concerns raised – TMC was the source of most concern where 74 legal guardians (p = 0,010) and 56 adolescents (p < 0,001) reported being worried, most being from Soweto. MMC caused fewer concerns, but almost all who reported concerns lived in CT for both legal guardians (p < 0,001) and adolescents (p < 0,001). The majority of legal guardians (n=74) worried about traditional circumcision (Table 12). Reasons for concern were safety of procedure (*n*=31), lack of expertise (*n*=17), pain (*n*=12), cost (*n*=8), inappropriate circumcision (*n*=2), missing school (*n*=1), not knowing what happens (*n*=1) and not specified (*n*=2). A total of 62 participants worried about traditional circumcision. Reasons for concern were safety of the procedure (*n*=23), pain (*n*=19), lack of expertise (*n*=9), cost (*n*=5), inappropriate circumcision (*n*=2), the tradition as a whole (*n*=2), the length of the tradition (*n*=1), not knowing what happens (*n*=1) and not specified (*n*=1). Around a third of legal guardians (n=29), mainly from Cape Town, worried about medical circumcision. Reasons given were unacceptance in the

community or family *n*= (9), against culture (*n*=9), not being regarded as a man (*n*=5), safety of procedure (*n*=3), cost (*n*=1) and pain (*n*=1). Again, around a fifth of adolescents (n=22), mainly from Cape Town, worried about medical circumcision. Reasons given included; not being regarded as a man (*n*=13), against culture (*n*=5), unacceptance in the community or family (*n*=3), cost (*n*=3), pain (*n*=2) and lack of expertise (*n*=1).

Motives for circumcision – Overall, 'protection from HIV and STI's' was the most popular motive for circumcision (Table 13), with 'religious or cultural' purposes and 'to become a man' coming in second and third. When disaggregated by site, Cape Town participants chose religious/ cultural motivations for circumcision most frequently. Almost all circumcised participants regarded 'protection from HIV and STI's' as the only reason for circumcision. In the uncircumcised group cultural motivations were more popular.

	Cape Town		**Soweto**		
	Uncircumcised n=49(%)	**Circumcised n=1(%)**	**Uncircumcised* n=38(%)**	**Circumcised* n=12(%)**	**Total (n=100)**
	Adolescent		*Adolescent*		
Religious / cultural	43(88)	1(100)	0	1(8)	45(45)
To please family / community	29(59)	1(100)	0	0	30(30)
To become a man	41(84)	1(100)	2(5)	0	44(44)
Hygiene	40(82)	1(100)	2(5)	0	43(43)
Protection from HIV / STI's	41(84)	1(100)	27(71)	9(75)	78(78)
To improve sexual pleasure	25(51)	0	0	0	25(25)
More attractive to women	17(35)	0	0	0	17(17)
It looks better	18(37)	0	0	0	18(18)

*Column does not equal total due to missing responses

Table 13: Adolescent motives for circumcision

Sexual risk behaviour – Pro-circumcision preference was not significantly associated with sexual risk behaviour, age of sexual debut, sexually active status over the course of the study, or age at enrolment.

Association between circumcision and research site – There were more circumcisions (TMC and MMC) in Soweto (n=12) than in Cape Town (n=1). Participants from Soweto were more likely to elect circumcision (TMC=1, MMC=11) than those from Cape Town (TMC=1) over time (HR 18.9, 95% CI 2.37-150.71, p= 0.006) (Table 14, Figure 3).

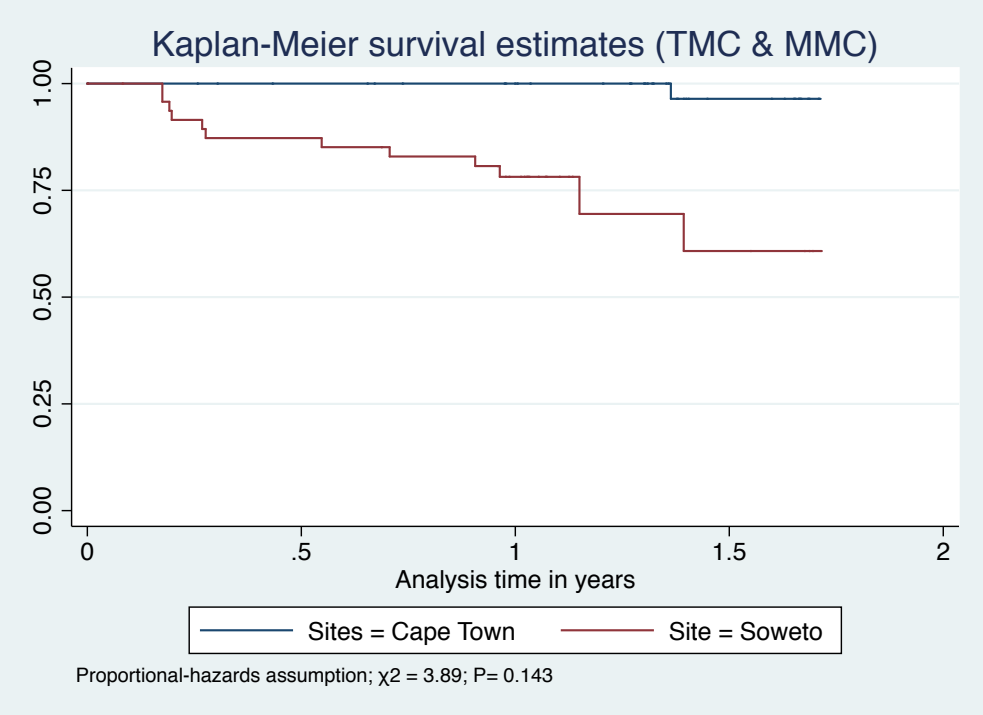

Figure 3: Kaplan Meier, survival time in days until circumcision (MMC and TMC) with Log-rank test for equality of survivor functions

	Unadjusted HR	(CI 95%)	p	Adjusted HR	(CI 95%)	p
Age (years)	1.36	0.80-2.31	0.254	1.16	0.64-2.12	0.630
Sites						
Cape Town	1 (base)					
Soweto	19.85	2.51-156.82	0.005	18.90	2.37-150.71	0.006

Table 14: Cox proportional hazard model: Association between time to circumcision

Discussion

While the uptake of circumcision overall was low in the study cohort, the Soweto component of the cohort contributed most to circumcision numbers and it is reasonable to assume that cultural traditions strongly influenced MMC acceptability and uptake. Despite reasonable knowledge about the benefits of early MMC bolstered by the men's sexual health educational sessions, the evidence from this study echoes the results of other research showing that many young males delay uptake (Mark et al., 2012), and Xhosa participants preferred TC to MMC. While research on circumcision in South Africa is rich, this study was novel because it followed young men in high HIV disease burden communities in South Africa at the time of sexual debut, finding that the diverse ethnic context had higher circumcision uptake. Additionally, the findings are useful because the study suggests that sexual health research and interventions should be designed for the intended context and population.

Soweto had higher overall circumcision uptake and MMC uptake. Xhosa participants accounted for a minority of circumcisions (three of the 13 circumcisions overall, and one of the eleven MMCs), even though Xhosa participants comprised the majority of study participants. Overall, three Xhosa speaking adolescents underwent circumcision in this age group. Since Xhosa males from Cape Town are circumcised between the ages of 19 and 21 years (Mark et al., 2012; Maughan-Brown et al., 2011), these participants may have had lower uptake of circumcision due to the preference of Xhosa males to undertake TMC when slightly older.

Although participants' and guardians' knowledge about the protection offered by MMC was high, and almost all participants reported wanting circumcision, uptake was generally slow and limited in this cohort suggesting some barriers or concerns. Concerns among the two cities were different: In Soweto, concerns were raised by participants and legal guardians with regard to safety of TMC. Conversely, concerns were raised about medical circumcision mainly among isiXhosa speaking participants. Their biggest fear was not being accepted in the community, going against their traditional practice, or failing to be regarded as a man if opting for MMC. Qualitative data may provide more detailed insights about the contextual and cultural influences upon circumcision uptake and how to adapt the service to the context.

There were a number of limitations in this study. While the age group was specifically chosen to investigate circumcision around sexual debut, very few participants elected circumcision in this time frame and it would have been instructive to extend the period of follow-up. Associations with circumcision status should be viewed cautiously because the cohort was small, which may have led to overestimated or missed associations. Finally, since TMC is culturally practised in Cape Town, there is far more acceptance here for this method of circumcision. This underlying ethos may also influence decisions for a number of reasons. Since most staff were also from the area, their cultural beliefs and practise may also have a significant role in influencing circumcision election.

Finally, bringing a behavioural economics lens to this research shows the importance of collaboration in designing sexual health interventions for AYA. Findings indicate that young Sowetan men were more inclined to adopt circumcision between the ages of 14 and 17 years during the study. The results of the study and those referenced in the literature review indicate that context and local practice in Cape Town greatly influence decisions. One of the strengths of participatory, iterative research is that researchers, community, and implementers get to design interventions together. The results suggest that it is always worth considering cultural adaptations, ideas, beliefs and mores that are part and parcel of the community or population. Collaboration assists integration into the specific

implementation settings. In short, it is enormously valuable to consider community participation when considering an intervention.

Recommendations – Male circumcision prior to HIV exposure appears to be an effective, once off intervention to protect heterosexual men from HIV acquisition. This is therefore an important male-specific tool in the prevention package for Africa where much of the HIV epidemic is fuelled by heterosexual sex. After King Shaka Zulu declared circumcision an unacceptable practice in the beginning of the 19th century, circumcision became unacceptable for around 200 years in Zulu culture. However, in 2009, Zulu king Goodwill Zwelithini decreed circumcision once again advisable due to the public health benefits. He stated that the current impact of HIV was a reason to change this cultural restriction. Male Circumcision is an integral part of the culture of a large part of South Africa. Programs to promote circumcision should take into consideration cultural and traditional mores including ensuring the cooperation of the cultural Xhosa leaders and people. Efforts should be made to ensure all circumcision is safe, culturally sensitive, effective and acceptable. Additionally, public messaging based on policy should be tested with target populations and their input should be used to ensure the message is heard as intended.

This study showed that, while circumcision is desirable as a prevention option which provides ongoing benefit for relatively little effort (Chapter one, figure 1), the mode of circumcision is dependent upon conventional practice. While men are encouraged to pair circumcision with another prevention method which may require deliberation and effort, the one-time procedure offers continued benefit and requires no further deliberation or effort. The higher adoption rates in Soweto bode well for scaling circumcision in that area. If young Xhosa men are to maximally benefit from circumcision, the cultural context, however, will be a fundamental consideration when designing this intervention where traditional circumcision is practiced.

Chapter six: Discussion and conclusion

"An ounce of prevention is worth a pound of cure" Benjamin Franklin.

If one can nudge towards benefit through designing choices, ethically, one should. This thesis set out to investigate what young people want in SHS, and then, using the behavioural economics model to frame the interventions, applied their elicited recommendations to design three differentiated services; a HIV diagnostic, HIV prevention and a service delivery platform.

Synthesis of results

The thesis objectives were, through iterative, participatory research:

1. To investigate what AYA want in sexual health services
2. To design and implement AYA recommendations for an:
    a. HIV diagnostic service
    b. HIV prevention service
    c. SHS delivery platform
3. To investigate the acceptability of the three interventions

Objective one: Chapter two answered the first objective of this thesis. In addition to listing barriers to seeking SHS, AYA offered suggestions to increase the desirability of these services. In agreement with the literature covered in Chapter one, three main themes emerged from the focus group discussions; convenience, tailoring and trusting relationships. Convenience translated into opening times, SHS proximity and visit duration. Since young people experience generic information and services as not useful, participants recommended that healthcare professionals tailor information and services to individual needs to improve personal relevance and utility. Lastly, participants recommended trust-building relationships to facilitate honesty on the part of patients, which in turn would promote dispensing more accurate information and services on the part of healthcare staff. Based on these recommendations, in combination with a behavioural economics framework, three interventions were developed and implemented.

Objective two: As AYA avoid SHS, nudges are required to increase the uptake of these crucial services in this vulnerable period of development. The three interventions included HIVST at youth-friendly clinics, circumcision in youth-friendly clinics, and a youth-friendly mobile SHS. First, testing with the HIVST device provided convenience and, while not particularly tailored for AYA, self-testing with the AtomoRapid fulfilled their request for confidentiality and privacy. Second, circumcision is a one-time procedure that provides long-term prevention effects. This intervention operationalised convenience

and youth-friendly staff to provide a prevention service tailored for young men. Lastly, since conventional, clinic-based SHS are largely unpleasant for AYA, a mobile SHS was developed and implemented. The mobile clinic provided a convenient, adolescent-friendly SHS delivery platform tailored for AYA.

Objective three: All three interventions achieved high acceptability in AYA. The mobile clinic platform study in Chapter three found that AYA preferred the mobile clinic to traditional clinic services on convenience, tailoring and trusting relationships. It was evident that mobile services saw proportionately more young men than the conventional clinics, and that the mobile clinic yielded more HIV infections than the conventional clinics.

In Chapter four HIVST was preferable to testing at a conventional facility and young people were able to complete the test correctly and correctly interpret their results. The findings show that young people preferred HIVST and thought it was more convenient than conventional testing.

Most notably, the circumcision study in Chapter five found that both the Cape Town and Soweto sites were keen to elect circumcision, but the cultural context contributed significantly to timing and type of circumcision. It was evident that context influenced MMC versus TMC election. As referenced in Chapter one, context can significantly shift behaviour (Kahneman, 2011; Wisman & Koole, 2003). Participants from Cape Town and their guardians, where TMC is culturally practised, were less likely than Sowetans to acknowledge the protection offered by MMC, even though all participants had been made aware of this. Accordingly, interventions, such as MMC, should be culturally adapted for the context, as mere replication could result in poor uptake, scepticism and rejection of the intervention.

Overall, using behavioural economics recommendations to design and implement AYA recommendations received an overwhelmingly positive reception.

Discussion

This section will first contextualise the studies' results, then discuss strengths and limitations of the research, and conclude by making recommendations for further research and implementation. South African AYA remain at high risk of HIV infection and associated illnesses (Bor et al., 2013; Nglazi et al., 2012; Wood et al., 2015) despite gains made in paediatric and older adult populations. AYA report that interactions at healthcare services take too long, are largely unpleasant and undermine trusting relationships between them and staff. These unpleasant experiences have caused young people to delay accessing diagnostic, prevention and treatment services until absolutely necessary. The

resultant missed opportunities for HIV testing, prevention and treatment have contributed significantly to the continued high rate of infection in this group.

System 1	System 2
Instinctive	Conscious
Little/ no effort	Effortful
Quick	Slower
Emotional	More logical
Automatic	Deliberative
No sense of voluntary control	Complex decision

Table 15: Behavioural economics two systems of thinking

When health behaviour is an opt-in choice, relies on effortful decision making and is likely to be an unpleasant experience, people (and particularly young people) are less likely to adopt health-seeking behaviours (Thaler & Sunstein, 2008). This passive strategy usually leans on the rational, conscious, effortful and deliberate motivation of the general population in response to educational messages (system 2, Table 15). Alternatively, it is frequently severe distress in the form of symptoms that drives health-seeking behaviour. In the case of HIV, a suboptimal level of health-seeking has led to the gradual growth of the HIV epidemic, and low health-seeking is also associated with high rates of HIV-related mortality and lower quality of life. Both HIV-related mortality and lower quality of life are significantly greater in men (versus women) and young people (versus older adults). Improving health and quality of life serve as an imperative to increasing health-seeking behaviour in South African AYA.

Young people frequently suggest that the desirability of the service, the ease of adoption of the behaviour, and the quality of the interactions with healthcare staff (system 1) are far more likely to promote health-seeking than information alone. Combining this knowledge with an understanding of adolescent brain development indicates that using reward and norm (affiliation) systems can significantly nudge motivation (Reyna & Farley, 2006; Victor & Hariri, 2016). When developing interventions it is crucial to consider that young people are more generally present-biased, affiliation-seeking and frequently delay undesirable experiences (Chang et al., 2017; Kahneman, 2013; Reyna & Farley, 2006; Simon, 1991; Thaler & Sunstein, 2008).

This thesis investigated what AYA want in SHS and then used the behavioural economics theoretical framework to develop interventions to nudge health-seeking behaviour in AYA in high HIV disease burden communities in South Africa. Libertarian paternalism was central to developing and investigating the acceptability and uptake of the interventions aligned with AYA recommendations.

Chapter two – AYA want to overcome personal and structural barriers

The focus group discussions taught us that AYA want to maintain good sexual health and they believed that tailored health services could overcome barriers and could even be desirable experiences. Ease of access and relationship building were the foremost themes in the focus groups. Many of the associated themes focused on relationships with healthcare staff, such as confidentiality, privacy, being understood and rapport. Certainly, relationship building is fundamental during this phase of psychosocial development and adolescents are especially sensitive to praise and derogation in relationships. At a minimum, interactions with healthcare should not leave young people feeling disparaged by the experience. Optimally, interactions should encourage efforts to seek out healthcare and should aim to build trust.

Although AYA friendly services will remove some of the relational barriers that individuals face, seeking and attending HIV services is unattractive for a few reasons. Firstly, seeking out HIV-related healthcare is highly stigmatised and still strongly linked with vulnerability, wasting and death. People are innately motivated to avoid thinking about their mortality, which is why it is so difficult to get people to adopt illness detection and prevention behaviours. Secondly, health-seeking has traditionally been framed around sickness. Young people are exceptionally motivated by reward and prone to present bias, more so than in later adulthood. Healthcare messaging and interactions with healthcare services should frame immediately valued outcomes. While valued outcomes are often conceived of as financial, the outcomes could encompass a wide range of benefits. One example might be a shift from framing the health behaviour from disease to a positive, socially valued frame, such as wellness. Oral hygiene has demonstrated that health behaviour can be presented as a socially valued outcome and not just the prevention of a long-term undesirable outcome. In this example, the valued outcome is the opportunity to interact and present oneself admirably and avoid social shame. Self-presentation and group norms are powerful motivators. A smelly mouth is unattractive and makes one socially unattractive, whereas a clean smelling mouth is socially desirable.

To make health services more desirable and to encourage health-seeking, AYA recommended considering tailoring, trusting relationships, privacy and confidentiality in the design of these services. The first study showed that AYA think that appropriate services could move young people from apathy to uptake by improving these aspects of desirability.

Chapter three – Contextually adapted services can pull the right crowd

The third intervention showed that an AYA dedicated mobile clinic can overcome structural barriers to provide a convenient, tailored, friendly SHS. These findings support recommendations to provide

differentiated care to AYA; the clinic attracted proportionately more young men and yielded more HIV than conventional facilities. Even though the mobile clinic was quite public and visible, counterintuitively, AYA reported that their experience was confidential and private. Social learning theory suggests that witnessing a model increases the likelihood of the behaviour occurring in those who have observed the behaviour. Modelling especially applies to complex behaviours, such as language learning and health-seeking. The public nature of the mobile clinic likely serves to reduce stigma and develop the narrative that getting a sexual health check is normative. Normative values have great potential to shift human behaviour, and therefore, can be used strategically to increase health-seeking. Moreover, presenting the service as a wellness clinic, designing the colourful exterior, and placing youth-friendly staff on board, facilitated in framing the service as exceedingly desirable.

The iterative, participatory design, drawing on the input of young men and women, was a definite strength of this thesis. It can be difficult to make health-seeking attractive because of the numerous barriers covered in Chapters one and two. Foregrounding the benefits of routine sexual health check-ups, accompanied with skilled counselling, can decrease the discomfort and denial that often accompanies the anticipation of healthcare visits and staff interactions. Because mobile services can decongest conventional facilities by task-shifting simple diagnostic, treatment, prevention, and care services to mobiles, future studies could investigate the optimal model and cost-effectiveness. It is valuable to understand the cost-effectiveness in time, money, quality of life and lives saved. Early models indicate that mobile services are cost-effective and help to avert lives lost because they identify positive diagnoses earlier than conventional facilities (Govindasamy et al., 2015), and therefore facilitate behavioural risk reduction and early treatment initiation. Future research could investigate the various combinations of tailored models, such as holistic diagnostic, treatment, and prevention SHS. This would greatly improve convenience and the cost should be investigated. Furthermore, it is advisable to use geospatial mapping to match appropriate services to the community need, thereby further enhancing the cost-effectiveness.

Chapter four – HIV self-testing has high acceptability, fidelity and usability

The HIVST intervention at the youth-friendly clinics tested whether young people could complete the test correctly, and investigated the usability and acceptability of using this potentially more private, convenient and autonomous diagnostic. Both debut HIV testers and those who had previously tested indicated that HIVST was vastly more preferable to the conventional facility-based testing. Additionally, young people could correctly complete the test and interpret their results. HIVST harnesses self-efficacy and convenience and so has great potential to improve rates of uptake, particularly for those who may delay testing at conventional testing services. While convenience is a

positive characteristic, future research should investigate appropriate and beneficial dispensing locations, such as mobile clinics, transport hubs, shopping centres and online courier services.

Since HIVST will likely take place outside of conventional clinics, follow-up remains a concern. Although self-testing allows for ownership of the testing process, there are currently very few follow-up and linkage-to-care studies. Barriers and facilitators are not presently well understood for people who would prefer self-testing. It is worth investigating appropriate and acceptable follow-up and linkage-to care options that make prevention and treatment easier to initiate after an HIV negative or positive diagnosis respectively. Mobile HIV test and treat clinics have recently been initiated in South Africa and may in part serve this function. While adverse outcomes related to HIVST are a concern, there is little evidence to suggest that this mode of testing has adverse outcomes. Future research on HIVST should continue to monitor for adverse outcomes.

More broadly, the results of this study suggest that young people were open to self-initiated diagnostics because of the convenience and ease-of-use. If use is intuitive, as was evidenced by the high usability of the AtomoRapid device, and the device is placed in convenient locations, diagnostic technologies could be tested in non-laboratory settings to improve uptake in young people who delay testing at more conventional settings. Providing self-initiated testing moves the process away from time-consuming conventional HIV testing settings which require system 2 deliberation, and leans towards quicker and easier system 1 of thinking.

Chapter five – Implement cultural and contextually adapted interventions

MMC, a one-time procedure completely removing the foreskin, can provide up to 60% protection from HIV infection for men engaging in vaginal sex and offers protection for women with circumcised partners. MMC provides a safe, one-time procedure for men who would like a long-lasting option to prevent HIV infection. In the limited two-year follow-up, the study showed that young men were willing to undergo medical circumcision. The most commonly cited reasons for circumcision in this study were to protect against HIV infection, religious and cultural reasons, progression to manhood, and for hygiene.

There were two partially expected results in this study. Firstly, although all participants had undergone information sessions about MMC, those from Cape Town were significantly less likely to acknowledge the prophylactic effect of circumcision against HIV than Sowetans. Secondly, participants from Cape Town were more likely than Sowetans to express concern about MMC, giving cultural reasons. This finding suggests that circumcision interventions should optimally be developed for the context. Ensuring that TMC is safe and effective is preferable to changing cultural practice. While literature

does not yet exist, Xhosa practise is increasingly employing medically trained circumcisers to ensure TMCs performed on young Xhosa men are safe, complete, and in an acceptable manner to those who practice the tradition. This is an enormously encouraging development.

It is tempting to design and provide an intervention only to discover later that poor consultation in the development and design of the intervention caused poor uptake. It is therefore essential to consider the implementation context for the intervention and to work with the community in its development and prior to its implementation. This approach aligns with the behavioural economics model in seeking to tailor interventions to the context to maximally nudge the desired behaviour.

Strengths, limitations and lessons learned

The research presented in this dissertation conducted iterative, participatory research with young people using a behavioural economics framework. The studies were designed to provide options that leaned upon system 1 thinking to improve the convenience and ease-of-use, tailoring for the specific population, trust-building and desirability. A strength of the study was the involvement of young people from design to assessment, making the work iterative and participatory, highlighting youth voices.

PrEP (pre-exposure prophylaxis) and Antiretroviral treatment (ART) adherence behaviour were not examined in this thesis. PrEP and ART require daily adherence to be effective which is challenging for South African AYA in high disease burden communities (Marcus et al., 2017). Until longer acting treatment and prevention methods become available, similar research should investigate interventions to support PrEP and ART adherence.

Even though questions were deliberately asked in multiple ways to avoid prompting positive assessments, the self-report assessment may still contain positive bias. The lack of a randomised design in the set of studies was a significant limitation in this dissertation. However, whilst randomisation is an important tool to test impact and effectiveness of an intervention, the spirit of this thesis was to deepen understanding of adolescent motivations through a behavioural economics lens. As such, the more descriptive observational nature of the empirical work has helped to deepen these ideas and contributed to the building of the health model. Including a study that had a randomised design may have strengthened the work. An evaluation incorporating a randomised control design to test this hypothesis is a next, important step. For this thesis, while acceptability was the third primary aim, building adolescent-responsive sexual health services drawing on behavioural

economics generally, and environmental design and liberal paternalism specifically, were the first and second aims.

While the services in these studies were tailored for AYA using system 1 thinking, the interventions could have benefited participants by enhancing the tailoring. One way of doing this may be to ask patients to state the reasons for visiting the clinic upon arrival and prior to seeing a counsellor. In a similar way to booking an appointment at a clinic, this might help to guide the conversation between patient and counsellor/ nurse. Though young people may choose not to disclose or may disclose something that is safer to share, enhancing tailoring of the service, and of the face-to-face experience will greatly add to trust-building between patients and healthcare staff.

Conclusions

The following paragraphs outline that habituated healthcare is crucially important for South African adolescents but is often thought of as inconvenient. Since young people frequently evade health-seeking and deny their vulnerability, behavioural economics provides extremely useful tools for dodging denial and improving health-seeking. Specifically, introducing convenience, ease, and trusting relationship improves SHS acceptability and increases uptake in at-risk, hard to reach youth.

Appropriate, regular and habituated visits to healthcare services in adolescence have the potential to prevent illness and unwanted outcomes, or diagnose illness early and support and promote healthy and productive living later in life. Young South Africans are keen to maintain their health and say they want health interventions that will overcome the multiple access barriers they face. Specifically, young people say that adoption rates are crucially dependent on how the services are presented.

SHS visits can be a hassle! Conventional messaging campaigns have focused on loss-framed messaging, and conventional clinic facilities are extremely time-consuming, fragmented, unfriendly, and hold the potential for diagnosis of a dread disease. Behavioural economics suggests that threat-based information may thwart adaptive behavioural responses. Threat produces anxiety and consequently motivates anxiety reducing defences that often do not lead to risk reduction and health-seeking behaviours. Messaging by healthcare campaigns and healthcare professionals often attempt to stigmatise patients into health behaviour, with the use of dry education and manipulation via guilt and shame. It is plausible that communicators do this because they have the best outcome in mind, but the means often do not convey care for the autonomy and initiative of the patient, and people are largely unmoved by these efforts.

Additionally, especially where risk is concerned, adolescents are dealing with relatively new experiences and are more prone than older adults to respond intuitively. For example, intuitive responses can be seen when we watch advertisements about cigarette-smoking causing death (Arndt et al., 2013). Specifically, threat-based messages may not induce higher intentions to adopt safer behaviour because it is easier to deny vulnerability or rationalise to distance oneself from risk (Taubman Ben-Ari, Florian, & Mikulincer, 2000). When we think about future threats such as terminal illness, we are unlikely to do the healthy thing because we are prone to act according to our intuitive response, "Not me, not now", especially when the intuitive response reduces anxiety, or better, is gratifying. We deny vulnerability because it is an efficient response to assuage anxiety. If a bus drives towards us, we can jump out of the road. Since we cannot react similarly to future threats, we adopt efficient strategies to reduce anxiety. We deny personal susceptibility to the threat, or we deny that the threat exists instead of adopting adaptive responses that reduce the chances of the unwanted outcome. Knowing that people predictably behave irrationally, we can design interventions that facilitate adaptive behaviour.

Behavioural economics makes sense of these patterns of irrational behaviour and offers potential options for circumventing vulnerability-denial. The theory starts with the understanding that context, relationship, and personally valued outcomes powerfully shape behaviour. Behavioural economics reminds us that people have a few primary motivators. We like to belong and we like feeling valued for some reason; our intelligence, our work, our possessions, our family, our group affiliation, our status, our giving and recognition for what we believe are positive aspects of our identity. Exceptionalising negative attributes, such as ill-health, or even the potential for ill-health, can be an unattractive prospect. These concepts have heretofore not been used enough as impactful public health tools and require further study in the South African context. What are pragmatic changes that can help increase health-seeking?

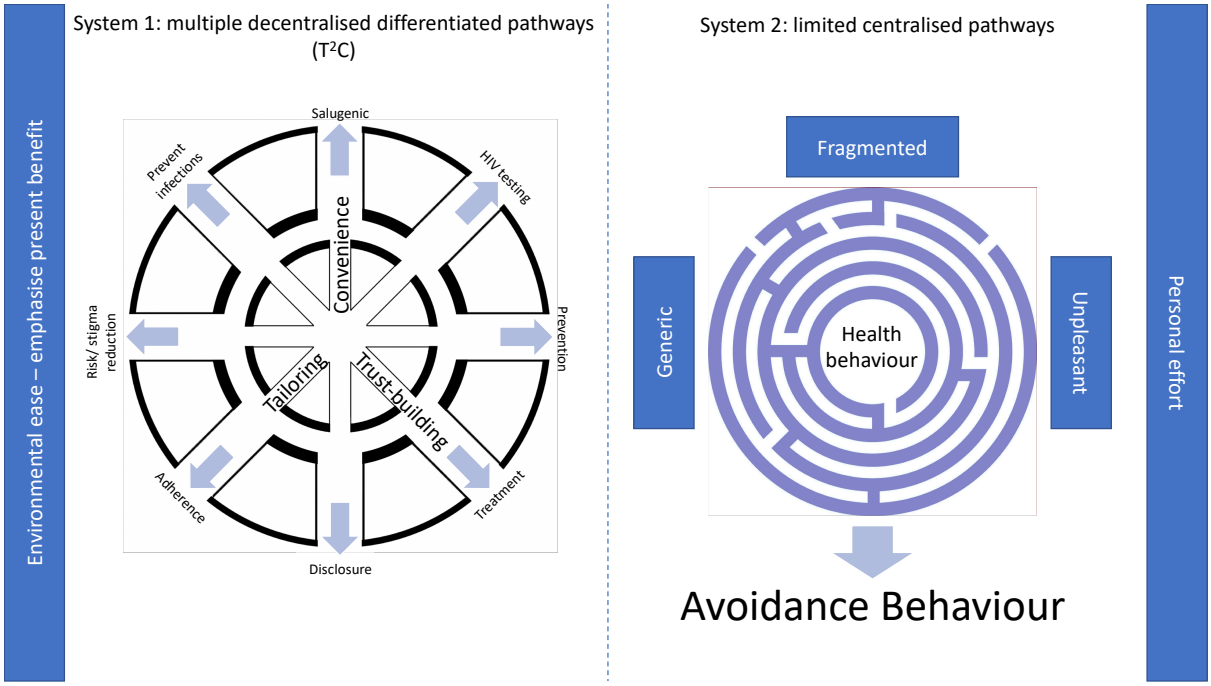

Figure 4: T²C Nudge health model

First, introduce ease and emphasise present benefit. Then, reduce discomfort. People generally bias away from feeling discomfort, which can reduce health-seeking, but bias towards easy gains. It seems obvious, but the cognitive dissonance around desiring health and avoiding undesirable experiences (e.g. HIV testing) has profound implications for health behaviour. Even though discomfort impacts health-seeking powerfully, it is surprising how small changes, such as making a behaviour easier to do, or tailoring the intervention, or emphasising present benefit can enable a behaviour for a young person. HIV testing is increasingly the gateway to global healthcare, including sexual health, contraception, diagnosis of non-communicable disease, disease prevention, and treatment options. HIV testing is, therefore, an opportune way of promoting health behaviours in South Africa. Since it may be too expensive to create dedicated healthcare for young populations, small contextual changes can bypass the ambivalence young people often experience and improve the convenience of health-seeking behaviour.

Based on the research presented here, there are practical steps that could increase health-seeking behaviour. It is important to start with the desired behaviour, and then design behavioural uptake for the intended population. We could improve relatability, tailoring, convenience (reduce proximity and the time required for behaviour adoption and increase ease). One example includes children's toothbrushes, which makes the health behaviour more tailored and relatable, and therefore more habituated. While it's important to address parents, multi-coloured toothbrushes can ease the habituation of the behaviour *for the child*.

First, improving the convenience of HIV testing is an example relevant to the current research. Waiting for people to initiate HCT is far less likely to encourage testing than community-based HCT, which brings services closer to people, increasing the likelihood of testing. The proportion of HIV-positive adults who were undiagnosed declined from more than 80% in the early 2000s to 23.7% in 2012 to 15.1% in 2017 (HSRC, 2018; Johnson et al., 2015), largely attributed to scaled-up of community-based HCT, including home testing, mobile and workplace testing. In addition, the T^2C model (trust-building, tailoring, convenience, figure 4) indicates that AYA should be presented with multiple pathways to health behaviours, which are centred on the individual, and which allow the individual to switch pathways. The research presented in this thesis converges with the evidence showing that changing the context to reduce discomfort and improve convenience can greatly impact acceptability and health-seeking. This is especially pertinent to AYA who are sensitive to relational and contextual feedback.

Second, tailoring is highly recommended for improving health-seeking in AYA (DiClemente et al., 2008; Pettifor et al., 2018). Evidence from the studies presented here suggests that interventions should be designed *with* the target population around their needs and challenges. System 1 in the model centres on the individual and tailors interventions accordingly. If young people identify with the presentation of the intervention and the interactions and information are tailored to their needs, adolescents tell us they are more likely to engage.

Lastly, relationship powerfully motivates health-seeking behaviour (Zanolini et al., 2018). This can be employed in a few ways. Having a buddy can improve the frequency of gym visits and medication adherence (Bärnighausen et al., 2011; Callaghan, Ford, & Schneider, 2010; Marino, Simoni, & Silverstein, 2007; Nachega et al., 2006). Alternatively, as presented here, friendly staff can improve the experience and health behaviour (Campbell, Scott, Madanhire, Nyamukapa, & Gregson, 2011).

As seen in figure 4, Kahneman and Tversky's behavioural economics model is attractive because it reduces reliance upon effortful decision making (system 2) and offers pragmatic, salutogenic pathways for increasing health behaviour (system 1). Additionally, the behavioural model should allow for switching pathways to further facilitate ease. Essentially, we don't have to be perfectly rational and abounding in motivation to adopt positive health behaviours. Although personal, non-rational motives and structural inefficiencies can prevent accessing healthcare, the consilience in evidence shows that small modifications can circumvent these barriers and improve both health-seeking behaviour and the acceptability of SHS. The following section will reflect on these results within the broader South African context, making recommendations for further research and implementation.

Recommendations

Many diseases thrive in marginalised communities which have increased levels of "… poverty, social isolation, overcrowding, poor education, and violence" (Smith, 2015, p 424). Although a strong link exists between HIV infection and the socio-economic environment, these conditions are unlikely to change rapidly through economic growth. Even so, ethical innovation that can increase intervention uptake is urgently required for young South Africans. The evidence presented in this dissertation indicates that we can design desirable interventions that nudge increasing numbers of at-risk young people to adopt health behaviour. At scale, innovative systems can improve the health and education of entire populations (Rosling, Rosling, & Rönnlund, 2018). Contextual adaptations that encourage predetermined outcomes, such as intervention uptake, can improve individual lives and public health.

The South African health system already creaks under the burden of disease, exacerbated by the annual increase in HIV infections, especially in young people. Recommendations for innovation in health services are as vital now as ever. Since increasing the number of healthcare professionals and creating dedicated services for populations or classes of illness are more aspirational goals, more affordable changes that can decrease the distance between the patient and healthcare are needed.

A behavioural economics model was used to develop and test innovations that young people suggested. The studies tested three innovations in service; first, the results indicate that convenience and supportive staff attitudes were highly valued by young people and that these should be high priorities for integration into SHS. Second, tools for rapid diagnosis made available in highly accessible places, or made available via home deliveries, can shorten the time to testing and diagnosis. Finally, interventions such as those tested in this thesis should be designed for their context. Taken together, the results of this thesis suggest that adolescents would benefit from differentiated models of care, including diagnostics, counselling, and tailored support through adolescent-friendly sexual health options. Until dedicated adolescent services are made available, scalable SHS adaptations integrated within the existing health infrastructure would greatly benefit AYA.

The structures for healthcare, such as HIV diagnostic and ART delivery services, already exist and are relatively familiar compared to newer delivery mechanisms. However, these conventional systems are outdated and have left patients unprepared and untreated, especially in hyper-endemic settings. Since South Africa needs scalable options to curb adolescent HIV infections (Pettifor et al., 2007), it is important to investigate innovative and cost-effective structural changes that could operate alongside or graft into already existing infrastructure (Pettifor et al., 2018). Using existing infrastructure can avoid high start-up costs, such as buildings and staff. Existing infrastructure includes the healthcare

system, the education system, and information technologies and telecommunications systems. These options should incorporate ease-of-use, desirability and trust-building.

Novel services have started operating across South Africa, including in limited resource, high disease burden communities. In conjunction with new developments in information technology that allows for digital recording of medical records, big data sets will allow for geospatially mapping HIV and developing strategically targeted interventions which are tailored for young people and their motivations (Pettifor et al., 2018). Highly specified interventions will direct services where they are most needed and most impactful. One unpublished example in Cape Town (based on Chapter three's research) is testing the use of mobile clinics attached to conventional clinic facilities. Briefly, this satellite model can improve the convenience of attending a clinic service for diagnostic services, and then refer into the connected conventional clinic for further intervention, including PrEP and ART.

Traditional health behaviour models tend to treat people as perfectly rational actors who behave to maximise personal benefit. But we know that people often do not act rationally, which can result in unintended outcomes. We know what we should do to maintain our health, but we tend to delay health-seeking or opt out altogether because it can be too laborious. Knowing this, behavioural economics has investigated tools that assist us in making healthy decisions that promote health-seeking behaviour. One of our key tasks in the public health space is to ensure that our available interventions are created for humans, to maximise individual and population benefits. This collection of studies has demonstrated acceptable, AYA centred interventions, that have nudged individuals into health-seeking. The barriers to health-seeking, including fragmented and inconvenient services, mistrust between staff and AYA, and confusing, generic information all contribute to cognitive strain and the subsequent desire to reduce that strain. The evidence in this thesis, following Kahneman (2011), recommends designers create cognitive ease to help nudge AYA health behaviour. In place of inconvenience, mistrust, and confusion, designers should ensure, convenience, trust and tailoring.

Stepping back, the Sustainable Development Goals (SDGs) centre on improving global wellness, specifically calling for an end to AIDS in goal three. While the extraordinary effort by the HIV community resulted in an abrupt reduction in HIV infections and HIV-related deaths, the epidemic continues to grow. SDG goal 3 (ensure healthy lives and promote wellbeing for all at all ages) will only be attainable through accomplishing universal health coverage, which is an extremely ambitious goal for limited resource contexts with frail healthcare systems (Bekker et al., 2018). Unless novel interventions are sought and implemented with the same vigour exemplified by the HIV community over the past three decades, we risk a rebound of the epidemic.

Accordingly, the future of healthcare is an important consideration. Future healthcare intervention will be increasingly personalised (Agyeman & Ofori-Asenso, 2015; Golubnitschaja & Costigliola, 2017; Nwaru, Friedman, Halamka, & Sheikh, 2017) for the individual and will be digitally automated (Ricciardi & Boccia, 2017; Sharon, 2017). The agricultural and industrial revolutions were accompanied by changes in education and, subsequently, in medical interventions, which drove down the cost of healthcare and increased its effectiveness. Similarly, the current information revolution has had wide-ranging impact, including big data and real-time analytics, which is increasing the personalisation of health interventions. Information technology has begun to influence healthcare prevention, detection and treatment interventions. Consequently, healthcare provision will become more meritocratic, where healthcare users will reward healthcare providers with their attention based on the providers' ability to provide convenience, ease, and tailored services. As a result, there will be an increase in the quantity and quality of care delivered. Diagnostics will be delivered directly to patients and there will be an option to notify healthcare providers, who will provide risk reduction and prevention or treatment interventions directly to the patient. In light of the quickening pace of technological advancement, and cognisant of the encouraging results presented in this thesis, health-seeking behaviour can increasingly become easier for vulnerable AYA. However, if we fail to centre interventions upon target populations, such as young South Africans, we risk missing those most in need and most prone to avoidance behaviour. As we embrace these new technologies, we must ensure that new and complimentary, multipronged interventions are designed for AYA centred delivery and are based on behavioural economics principles. This will ensure that new options combined with the continuing efforts of the HIV community will more effectively encourage health-seeking, self-management and wellness in young South Africans.

Conscious design, using behavioural economics to account for biases that prevent health behaviour, can result in health behaviour uptake. Additionally, informational interventions should be paired with environmental design to ease the uptake health behaviour. Commonly, informational interventions are designed to motivate individuals to take up diagnosis, prevention and treatment. However, the slow decline in new HIV infections and high mortality rates in adolescents indicates suboptimal uptake. There are numerous personal and social barriers for AYA, and in South Africa, these are amplified by the cultural, legal, political, and structural barriers. While there have been significant political and legal improvements which promote adolescent health, implementation has been slow. Ordinarily, interventions have been medically framed, but people would rather not think of themselves as at risk, and balk at the prospect of vulnerability, wasting and death.

There are, however, ways to design services to overcome the personal and social barriers, which is where an approach using behavioural economics can improve AYA engagement. Behavioural economics uses the psychological underpinnings of human behaviour by designing interventions for ease and desirability. Ease and desirability can overcome the external barriers and the internal cognitive dissonance preventing uptake. The evidence presented here showed that we can design more desirable interventions for potentially undesirable experiences. Chapter three showed that, in addition to creating a more desirable experience, that debut HIV testing was high and new HIV positive diagnoses were higher than at the comparable conventional clinics. Deliberate healthcare service design has the potential to meet the vulnerable where they are and to provide the services to those most-at-risk, and those most in need. Human biases can be overcome through environmental design.

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