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“They’re treating us bad now, never the same”:
Young people’s perceptions of health services in
Soweto, South Africa:
A qualitative investigation

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“They’re treating us bad now, never the same”: Young people’s perceptions of health services in Soweto, South Africa: A qualitative investigation

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An abstract of
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Abstract

Background

Previous research has indicated that South African youth feel estranged from health care facilities and health care workers, and as a result are more reluctant to seek out medical treatment, tests, or counseling. In 2006, the South African Department of Health adopted and scaled-up loveLife's Youth Friendly Services (YFS) initiative to a national policy to improve youth utilization of health services by strengthening counseling services and community sensitization. As YFS services roll-out, alternative services to target young people are also becoming more popular. Success of any of these services, however, is dependent upon a greater perception of health services as a whole.

Objective

This project aims to examine the knowledge of YFS initiatives, perceptions of current health services, and opinions on alternative health interventions for future implementation.

Methods

The study was conducted in Soweto, South Africa utilizing the Birth to Twenty (BT20) cohort. Twenty-five in-depth interviews were conducted between May-July 2012. Twenty-three of these were utilized for analysis according to modified grounded theory.

Results

Overall, knowledge of YFS programs was very low and no participant was able to express deep knowledge of the program's purpose or activities. In general, young people are dissatisfied with the current health services in Soweto due to a lack of resources, long waiting times, and poor quality of care heightened by an underlying lack of choice and perceived inequity. With regards to alternative services, there was no particular service that was preferred over another (8 YFS, 6 SBHC, 9 CHW).

Conclusions

Assurance of implementation of YFS standards should occur in all public health clinics with improved outreach and marketing in nearby communities. In-service training of nurses should be prioritized for all clinics with a focus on sensitivity to young people and equitable treatment to all.

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Chapter 1: Introduction

1.1 Background

South Africa is burdened by the weight of multiple epidemics that are disproportionately affecting adolescents (defined by the World Health organization as ages 10-19) and youth (ages 15-24). Together, these groups are defined as “young people,” those aged 10-24[1]. Young people comprise an important segment of the population, to whom early intervention can affect life-long choices and reduce the burden of disease. Previous generations relied heavily on family and community structures to provide health information and support. But as young people begin to exert more independence from these traditional social structures and rely more on peers, social media and technology, newer avenues to encourage positive health behaviors through early education need to be developed. Additionally, when education and prevention are not enough, efforts should be made to encourage and facilitate clinic utilization.

Realizing this need, South Africa’s Youth Friendly Service (YFS) initiative (formally the National Adolescent Friendly Clinic Initiative or NAFCI) was developed in 1999 as an NGO-led program through loveLife, South Africa’s largest national HIV prevention initiative for young people[2]. It sought to improve adolescent utilization of health services by training service providers, improving facilities, strengthening counseling services and incorporating peer outreach[3]. By 2001, the program had expanded to all nine provinces and by 2005 was practiced in 305 health facilities throughout the country[2]. YFS was officially scaled up to a national policy and adopted by the South African Department of Health in 2006[4]. This scale-up has proven difficult, in part due to the decentralized system in which it exists as well as the deeper history of

inequities in services that continue to affect perceptions of quality and trust in the health system[5].

1.2 Purpose

Much work has gone into the establishment and scaling-up of YFS initiatives in South Africa. This paper firstly aims to assess the knowledge of YFS initiatives among young men and women to evaluate if this effort has reached its intended population. Secondly, because these services exist in a system with a deeply rooted history of inequality that systematically discriminated certain populations through the racist policies of Apartheid. Attitudes towards health services should be examined to understand how this context might impact perception and utilization. Lastly, if current YFS initiatives are not sufficient to meet the needs of young people, attitudes and beliefs towards alternative health services should be evaluated to direct future programming.

1.3 Significance

Simply not knowing about available health services, such as YFS, is an important barrier to seeking out healthcare. However, there are many barriers young people face when deciding to use health services including, but not limited to, the perceptions of quality, confidentiality, and acceptability of the services. Therefore, it is necessary to examine the general perceptions shared by young people towards current health services to better understand the system in which YFS is implemented.

Furthermore, in working to improve health among young people, several alternative health services have been proposed including School Based Health Clinics (SBHC) and Community Health Worker (CHW) models. Evaluating the attitudes towards

these services by young people may provide insight on if these services would be deemed acceptable if rolled-out in local communities. Findings from this research may better define the current state of YFS and health services in Soweto, and provide guidance for approaching adolescent health services in the future.

1.4 List of Acronyms

Acronym	Definition
AIDS	Acquired Immunodeficiency Syndrome
BT20	Birth to Twenty
CHW	Community Health Workers
DALY	Disability Adjusted Life Years
HIV	Human Immunodeficiency Virus
IRB	Internal Review Board
LMIC	Low- and Middle- Income Country
NAFCI	National Adolescent Friendly Clinic Initiative
NCD	Non-Communicable Disease
NGO	Non-Government Organization
OTC	Over the Counter Drug
RHRU	Reproductive Health Research Unit
SBHC	School Based Health Clinic
SES	Socioeconomic Status
SP	Simulated Patient
STI	Sexually Transmitted Infection
TB	Tuberculosis
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
YAHS	Young Adolescent Health Survey
YARHP	Youth and Adolescent Reproductive Health Program
YFS	Youth Friendly Services

Chapter 2: Literature Review

2.1 The State of Adolescent Health Worldwide

At 1.8 billion, there are more young people (aged 10-24) on Earth now than at any point in human history[6]. While young people are generally regarded as healthy, this is a period whereby individuals pass through physical, psychological, and sexual maturation that influence health and determinants of health later in life. With the acceleration of globalization and the breakdown of traditional health systems, this generation faces very different challenges to their health than their parents did[7]. A reduction in infectious disease, under-nutrition, and infant mortality has shifted burden and attention to the growing prevalence of sexually transmitted diseases, substance misuse, injury and chronic disease that become prominent during adolescence[8];2.6 million young people die each year- primarily from accidents, violence, and sexually related illness that can be prevented[8].

Sawyer et al. (2012) discuss the blend of biological and social transitions that occur during adolescence and their important link to health. The timing of puberty has long-since been linked to the onset of sexual activity. Historically this was accompanied by traditional social maturation into marriage and childbearing. But over the last century the age of puberty has steadily decreased and the age at which individuals take on adult roles has increased, lengthening the time in which individuals are sexually active outside the traditional context of marriage[8]. When combined with the early onset and heavy consumption of alcohol increasingly seen in both girls and boys, the likelihood of risky sexual behavior is elevated[8]. More than 100 million sexually transmitted infections (STIs) occur among people under 25 each year[2]. Half of the Human Immunodeficiency Virus

(HIV) incident cases occur in people under 25, making it one of the leading causes of disease burden for young people[9].

This is amplified in low-income and middle-income countries, where adolescents face poverty, low rates of education, and increased rates of unemployment. When matched with limited access and availability of appropriate health services, these populations face increased risk of substance misuse and risky sexual behavior leading to HIV and STIs as well as unwanted pregnancies, unsafe abortion, maternal mortality and morbidity, and sexual violence and abuse[10]. These outcomes highlight the need for earlier intervention and better access to appropriate sexual and reproductive health education and services.

The period of adolescence also coincides with heightened sensitivity to peers, which often results in experimentation with substance misuse and other risky health behaviors. Alcohol use in young people accounts for 7% of incident Disability-Adjusted Life Years (DALYs) in young people worldwide[8]. Young people who begin drinking in early adolescence (aged 10-13) are more likely to become alcohol dependent within 10 years and have life-long dependence than those who begin drinking at an older age[11]. Matched with the increase in youth unemployment in many countries, there is greater risk for early substance misuse and mental disorder. Seventy-five percent of mental disorders present before age 24, and 50% before the age of 14[12]. Neuropsychiatric disorders are the leading cause of disability in young people (aged 10-24)[12]. Self-inflicted injury is the second leading cause of death among this population (aged 10-24)[8]. In addition to immediate injury and illness, behaviors that begin in adolescence have effects that can reach well into adulthood.

Nearly 2 in 3 deaths every year are attributable to non-communicable diseases (NCDs)[8]. An estimated 70% of these premature adult deaths are attributable to behaviors often emerging in adolescence, including smoking, poor eating habits, low levels of physical activity, and alcohol consumption[6]. The periods of adolescence and young adulthood offer opportunities to achieve long term health gains by intervening when attitudes and behaviors are not yet fully established. Yet, the success of interventions depends on limiting the number of barriers young people report when utilizing health services[9].

Barriers have been broadly categorized as barriers in availability, accessibility and acceptability. In developing countries services might simply not be available, and in countries where they are available, restrictive laws might prevent young people from accessing them[9]. Other accessibility barriers include cost, convenience, and a lack of knowledge of the services available and what they offer[13]. Acceptability is heavily dependent upon pre-existing perceptions, peer influence, and personal experience. Lack of confidence in the providers' knowledge, ability, and confidentiality are common barriers for young people in considering use of health facilities[14]. As a result, youth have reported feeling estranged from health care facilities and are more reluctant to seek out medical treatment, tests, or counseling[15]. To reduce morbidity and mortality related to young peoples' vulnerability and resistance to seek care, greater effort needs to be made to address the unique attributes, needs, and priorities of this population.

2.2 Adolescent Friendly Services

Recognizing that an improvement in adolescent health is an investment in long-term improvements in society, in 2001 the World Health Organization (WHO) published

a statement: *Global Consultation on Adolescent Friendly Health Services.* This publication formalizes the recognition of adolescent health needs and the importance of establishing health services to meet those needs, defining the characteristics of youth-friendly health services based on the principles of equity, accessibility, appropriateness, and effectiveness (Table 1)[1]. These characteristics have been developed through reviews of evidence and experiences of organizations that have worked with young people to remove these barriers. Research from various US- and UK-based studies has shown that young people exposed to adolescent-friendly interventions are more aware of, and reported increased access to, these services[9]. More needs to be done, however, to translate these practices to long-term, comprehensive policies and programs within the countries studied, as well as better examine implementation and impact in low- and middle-income countries (LMIC).

Table 1: Characteristics of a Youth Friendly Service, WHO[1]

- Staff that are specially trained to meet the needs of young people
- Staff that respect the privacy and confidentiality of services rendered
- Staff that spend adequate time to attend to the client
- Clinics where peer educators are available to young people
- Separate space and time for young people
- Hours that are convenient to young people
- Convenient location of services
- Youth involvement in services
- Short waiting time
- Affordable or free services
- A wide range of available services with limited need to refer

The adolescent health burden is particularly heavy in LMIC where young people comprise a greater proportion of the population than in high-income countries[8]. It is

therefore even more important that appropriate and effective interventions are in place to deal with the unique challenges and opportunities of a growing adolescent population within these contexts. While there have been several interventions to address the health needs of young people, the majority of successful adolescent-friendly services programs are small-scale, short-term, and low-coverage[16].

Two examples of youth-friendly services programs come from Zimbabwe and Kenya where community-based interventions aimed at reaching unmarried youth (aged 10-24) were established in 1997 and 1995 respectively and evaluated in 2005 by Erulkar, et. al[17]. Through a randomized, house-to-house survey, Erulkar et. al set out to determine which characteristics were most important to adolescents regarding health services. While at the time of this study these programs had not been incorporated into government policy or practice, they do reflect the commonly agreed upon attributes of adolescent-friendly health services as laid out by the WHO. A list of characteristics were read aloud to participants to which staff attitudes, confidentiality, short waiting time and low (or no) cost were rated as the most important characteristics[17]. Youth-only services, youth involvement and age/gender of staff ranked among the least important characteristics[17]. These findings imply that existing services may be in a position to improve their level of youth friendliness without having to construct new centers.

In Tanzania, adolescent-friendly program, MEMA kwa Vijana (MkV2), relies on in-service training of health service workers and scaled up through existing government structures[18]. Renju et. al. (2010) measured the impact of the program from both user and provider perspectives. The study involved a multi-dimensional evaluation including focus group discussions and semi-structured interviews with health workers and trainers,

training observations, and simulated patient (SP) evaluations. Data indicate that, overall, health services performed better in intervention health facilities even after scale-up for several points of quality including: health workers' attitudes, respect for privacy, waiting times, and cost of services[18]. In many health units (both adolescent-friendly and non-adolescent-friendly), however, services were rushed, did not collect comprehensive patient histories, or provide adequate information[18]. The authors concluded that in the context of a scaled-up adolescent-friendly program, intervention quality may be diluted particularly in regards to the high turn-over of staff and conditions of employment[18]. The Renju study is particularly unique in that it evaluates a scaled-up adolescent-friendly project in a LMIC. This thesis examines a similar program in the South African context.

2.3 Adolescent Health and Health Services in South Africa

Young people between the ages of 10 and 24 years comprise the largest and fastest growing population in sub-Saharan Africa; nearly one-third of the population of South Africa falls within this age range[19]. With the simultaneous occurrence of four epidemics - HIV and tuberculosis; a high burden of chronic illness and mental health disorders; deaths related to injury and violence; and rising rates of maternal, neonatal and child mortality - attention must be paid to health services catering to populations particularly at risk[20]. Policy makers have responded inadequately to the knowledge that these epidemics disproportionately affect young people[8].

In South Africa, the average age at first intercourse is 15 years for boys and 14 for years for girls[2]. Nearly half of young women have given birth before the age of 20 with 66% reporting that the pregnancy was unwanted[21]. While HIV has affected all age groups, young people have been hit hardest, as HIV prevalence is now at 13.6% among

young women and 4.5% among young men[22]. In spite of this, many young people do not use health services and have reported barriers when they do attend clinics[15].

In light of the growing HIV epidemic, loveLife was established in 1999 as a joint initiative of leading South African Non-Government Organizations (NGOs), private partnerships, and the South African government[23]. loveLife took a multi-faceted approach to a national HIV prevention and sexual health education program. They used a range of strategies including print and media education campaigns, peer education (groundBREAKERS), outreach and mobilization, and 18 pilot youth-friendly centers (Y-Centres)[2].

In 2000, the Population Council and the Reproductive Health Research Unit (RHRU) compared three different health service centers: loveLife Y-Centers, UNFPA-DfID Youth and Adolescent Reproductive Health Program (YARHP) clinics, and provincial clinics. They asked young people within each clinic's target area about their knowledge, access, and utilization of the center. Individual health outcome benefits could not be measured because these program co-exist with a variety of other interventions that have similar health goals[23, 24]. Overall, loveLife Y-Centers scored highest in knowledge of centers, equity in access among gender, and improved access to clinical services[25].

At the same time these results were coming out, The National Adolescent Friendly Clinic Initiative (NAFCI) program was being conceptualized by RHRU. It was developed as a training and accreditation program for public health clinics that would be implemented by the loveLife trust. NAFCI developed a set of 10 "adolescent-friendly" standards on which clinics would be evaluated (Table 2)[3].

Table 2: NAFCI Standards[2]

1. Management systems are in place to support the effective provision of adolescent-friendly services.
2. The clinic has policies and processes that support the rights of adolescents.
3. Clinic services appropriate to the needs of adolescents are available and accessible.
4. The clinic has a physical environment conducive to the provision of adolescent-friendly health services.
5. The clinic has drugs, supplies and equipment to provide the essential service package for adolescent-friendly services.
6. Information, education and communication consistent with the essential service package are provided.
7. Systems are in place to train staff to provide adolescent-friendly services.
8. Adolescents receive an accurate psychosocial and physical assessment.
9. Adolescents receive individualized care based on standard service delivery guidelines.
10. The clinic provides continuity of care for adolescents.

Bronze, Silver, or Gold Star levels of accreditation would be awarded on the basis of a self-audit and an external assessment of the number of standards achieved[2]. The key objectives of the program are to make health services more accessible and acceptable to youth by establishing standards and build the capacity of health workers to meet these standards[2]. A lack of consistency and sustainability of these initiatives has been an inherent risk of the program as it was centrally designed but control of implementation is at the provincial level.

As a pilot, the program was run by loveLife, incorporating groundBREAKERS at NAFCI sites to provide interface between clinics and community. NAFCI was piloted for approximately 18 months and then scaled up to a national program[2]. In 2003, the program began its major roll-out of the program and by 2005, 350 clinics were participating in the NAFCI program with an additional expected roll out of 171 youth-friendly clinics by

local health service structures[2]. In 2006 the Department of Health took over administration and renamed the program Youth Friendly Services (YFS). The model continued to address aspects of prevention, risk reduction, information sharing, and service delivery for all South Africa, yet scaling-up has proven difficult. Oversight and training of the groundBREAKERS was decentralized to each clinic and many peer educators reported not receive adequate orientation or support[2]. While the NAFCI program proved to be successful during its pilot stage, there have been few examinations of YFS post scale-up.

One study, conducted by Mathews et. al, reviewed the effect of YFS on quality of HIV testing services for adolescents in Cape Town post scale-up in 2005. They utilized simulated patient (SP) tests to assess accessibility and acceptability factors for Voluntary Counseling and Testing (VCT) services. The most notable finding from the Mathews et al. study was that there was no statistically significant difference in adolescents' experiences of negative attitudes from workers and confidentiality breaches between YFS and control clinics. Timeliness was also seen as problematic in both control clinics and YFS clinics, varying between 30 to 335 minutes (median: 120 minutes)[26]. The authors indicated that accessibility, measured as SP being turned away for HIV tests, was better in clinics providing the YFS program than in control clinics. However, no measures of financial or geographical barriers could be taken, as this was a SP experiment and transportation to and payment for the services was ensured by the program[26]. This is important to note given the extensive literature highlighting geographical and financial barriers in accessing health services[13, 14, 27].

In a 2006 study, Richter and Mfolo examined accessibility barriers and perceptions of health services. In this assessment, the authors conducted a survey among 119 young people aged 14-19 years, who attended a certain health center in Hammanskraal, South Africa[15]. While the authors did not indicate whether the clinic was YFS-accredited, the study gives a greater sense of young people's feelings towards primary health care services overall. In general, the study found that the participants did not find health services particularly "friendly" toward young people. Perceived barriers in accessing certain services included discomfort, age, gender of health care workers, or ability to pay[15]. Participants suggested creating a greater awareness of youth services and considering cultural appropriateness and issues related to the decentralization of services when trying to make them more accessible.[15]

These last two points are particularly poignant given the tumultuous political, social, and economic landscape of South Africa. To better understand the disparities in adolescent health, it is important to recognize the deeper context and history of inequities in health services within South Africa.

2.4 Historical Context of South African Health Services

Addressing the needs of young people goes beyond addressing the scope of health services alone. Legal policies, social frameworks, and cultural norms are just some of the important aspects that acutely affect the health outcomes of young people. This is particularly true in South Africa which has a complex and deeply-rooted history of structural and social inequalities.

The country was molded by the violent appropriation of land and resources from an indigenous majority and their continued oppression for the benefit of the white

minority. The formal state policy of apartheid was established in 1948 which fortified and formalized a standard for segregation and injustice[20]. The system was based on a racial hierarchy with European (white) at the top followed by Asian (Indian), Coloured (mixed-race), and finally Bantu (black) at the bottom[*]. This classification determined where a person could live, work, and the resources allocated to them- including social services such as education and health.

Because of these policies, people were forcibly relocated to government-approved locations. Black populations were primarily located in urban townships and rural bantustans where conditions were poor at best, resulting in increased rates of morbidity and mortality from communicable diseases such as tuberculosis[20]. As conditions continued to degrade, discontent grew. Anti-apartheid organizations within the country became widespread and militant, met with a state violence and extreme repression in the townships. After decades of political resistance, democracy was won in 1994 and a democratic constitution to uphold human rights for all South Africans was established[20].

But by the time apartheid had ended, institutional segregation had become so deeply entrenched as a social norm that movement forward proved to be difficult. Wealth disparity (as measured by the Gini coefficient) actually grew in the first decade of democracy, increasing from 0.56 in 1995 to 0.72 in 2005, as policies to increase economic growth continued to benefit the white population almost exclusively[20].

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[*] *The use of the terms 'black', 'coloured' and others established through early segregation policies does not imply any acceptance of the racist assumptions on which these labels are based. Instead, they should be seen as a reflection of the impact of apartheid on the lives of various groups in South Africa.*

This economic and racial disparity reverberates into the greater social system, including health system access and outcomes. Racial, socio-economic, and rural-urban differences in health outcomes and access in and between the public and private health sectors remain challenging. Several studies have captured the disparities that exist in health status in South Africa, echoing the racial hierarchy created by apartheid (Table 3). Disparities exist among not only communicable diseases such as tuberculosis (TB) and HIV/AIDS which have been widely reported, but also in rates of non-communicable diseases and injury.

Table 3: Health Disparities by Indicator in South Africa

Health Indicator	Disparity
HIV/AIDS	Prevalence estimates for HIV show that white and Indian men and women have a very low prevalence (0.6% and 1.9% respectively), whereas the highest prevalence is found in the black population (13.3%)[28].
TB	Compared to Africans, Whites were significantly less likely to have had either recent or lifetime tuberculosis (OR 0.12 CI 0.02-0.84; OR 0.46 CI 0.25-0.86 respectively)[29].
Infant Mortality	Infant mortality rates vary between 7 per 1000 in the white population and 67 per 1000 in the black population[20].
Obesity	Black African women are more likely to be obese than Coloured, Indian, or White races. 25.9% of Black women are classified as overweight; 31.2% as obese[30].
Life Expectancy	Life expectance for white adult women is 50% longer than it is for black women[20].

A key to reducing health outcome inequalities is improving access and quality of health services for those who had been previously shut out of public social services. The system that had existed before 1994 was hospital-based, curative, and mainly targeted to the white population[5]. Only 11% of the total health expenditure went toward primary

health care services used almost exclusively by the black population[5]. In addition, public health expenditure was three to six times higher in wealthier districts than in poorer districts[5]. When apartheid ended, the national department of health developed a "functions committee" to determine more equitable distributions of funds that reallocated resources from previously advantaged provinces to historically disadvantaged provinces[5]. However, the limited capacities of under-resourced provinces have resulted in a mismanagement of funds and resources, increasing the inequalities in inter-provisional health budgets[5].

This disparity is aggravated by the decentralization of the public health system. When the constitution was written, political negotiation put in place sets of intergovernmental structures that reorganize responsibility with strong dependency on peripheral agencies for implementation. Three spheres of government were created- 1 national, 9 provincial, and 284 municipalities- to greater strengthen local governance and accountability[5]. Service delivery - including health services - is devolved mainly to the lowest sphere of government. What has resulted is a conflicting blend of "one-size-fits-all" policies with varying local municipality capacity and interest[31].

This has led to considerable variability in quality of public health service clinics between municipalities. While some clinics have the capacity to carry out National Department of Health recommendations, others continue to struggle. Limited capacity matched with low resources has led to frequent drug stock-outs, inadequate or no diagnostic equipment, and insufficient skilled staff in some local clinics[32]. McIntyre and Klugman additionally noted that while resources are an important constraint, morale (influenced by many factors including dissatisfaction with managing support, salaries,

and conditions of employment) may have the greatest impact on provision of quality health services[31]. Low morale reflects back to the patient as poor staff attitudes and undermines patient confidence in the skills of health workers.

One way to access higher quality services is to purchase medical aid insurance or pay out of pocket for private services. However, accessing these services for many people is often financially unfeasible. Medical schemes available in South Africa are regressive, in that the lower income populations pay a higher proportion of their household income than higher income populations. This often excludes lower socio-economic status (SES), typically black, populations from buying into these schemes. About 15% of population has medical aid; 60.8% of these are within the top income quintile[33]. Very few people in the lower quintiles are covered by medical aid, and therefore continue to rely on over-burdened, low-resourced, free public clinics.

Choice in access is further suppressed within these public services. According to the 1996 Center for Health Policy's *Plan for Primary Health Care*, patients are required to utilize the services nearest them[34], even if they consider this clinic of lesser quality than a clinic farther away. So patients that are already limited by the financial barrier of accessing higher quality private services, now face a geographic mandate that strips them of their freedom to access more acceptable free health care. Because of the overwhelming barriers that continue to exist, many simply choose to avoid health services altogether. In a 2008 survey, Kon and Lackan reported that 40.8% of Blacks and 22.9% of Coloreds went without presumably needed medical care at some point in the past year, compared to 10.9% of Whites and 6.9% of Asians[35], paralleling resulting disparities in health outcomes and health care access.

Programs have been developed to encourage and facilitate better utilization of health services. These programs exist, however, in a larger health system with a deeply rooted history of health inequality and discrimination. It is important to understand how this context effects attitudes towards current and future services to better address and improve long term health outcomes and reduce health burden. The following study will explore knowledge of YFS, attitudes towards alternative health services, and how historical social disparities can effect general perceptions and utilization of health services.

Chapter 3: Methods

This is a cross-sectional qualitative research study with participants in the Birth to Twenty (BT20) cohort in Soweto, South Africa. This chapter will describe the methodology used in collecting and analyzing data to meet the project objectives.

3.1 Setting and Sampling

The Birth to Twenty cohort is the largest and longest running study of child and adolescent development on the African continent. During a seven week period in 1990, 3,273 children born in public hospitals in the Johannesburg-Soweto area were recruited for a long term study on health behaviors and outcomes. Since then, these children and their families have been monitored by research staff. Attrition over two decades has been comparatively low (30%[36]), occurring primarily during children's infancy and early childhood. Approximately 2,300 young people and their families remain in contact with the study. The sample is roughly representative of the demographic and racial profile of South Africa with equal numbers of male and female participants[37].

The present study was conducted from May to July 2012 in Soweto, South Africa. Twenty-three Black African young men and women were purposively selected from a subset of fifty BT20 cohort members. This subset had been randomly-selected from the full cohort to participate in a pilot of the periodic Young Adolescent Health Survey (YAHS). The sub-set of participants for this study were chosen based on gender (14 female/ 9 male) and utilization of health services within the last six months (15 users/ 8 non-users). All participants were either 21 or 22 years of age at the time of interview.

3.2 In-depth Interviews

An in-depth interview guide was developed prior to the study (Appendix A). This interview guide was developed through a thorough review of the literature and modified through informational interviews with field staff in Soweto. The interview guide explored perceptions and use of health services as well as underlying social context. Four internal interviews with research staff members were conducted to pilot the interview guide and determine if the questions were culturally appropriate.

A BT20 staff member contacted each participant by phone, explained the nature of the study, and invited subjects to come in for the interview (Appendix B). Each participant was compensated for travel expenses and provided with a snack. Interviews were held on-site at the BT20 offices at Chris Hani Baragwanath Hospital in private interview rooms. Informed consent was obtained from all individuals who participated in the study (Appendix C). The protocol was submitted and exemption granted by Emory University IRB (ID 58317; Appendix D). Local ethics approval was granted by the University of Witwatersrand under the BT20 approval (ID M120138).

Five external pilot interviews were conducted with members from the YAHS subset of the Bt20 cohort to refine the interview method. Three interview methods were piloted: (a) traditional 1-on-1 interview between one of the PIs and the participant in English, (b) traditional 1-on-1 interview between a Zulu-speaking research assistant from the community and the participant in Zulu and English, and (c) interview between one of the PIs and the participant with the Zulu-speaking research assistant present for translation if the participant felt more comfortable expressing themselves in Zulu during the interview.

Through the external pilot interviews, it was determined that participants were the most comfortable expressing their opinions in the semi-structured 1-on-1 in-depth interview between the PI and the participant in English (option a). More complete answers were elicited from the 1-on-1 in-depth interview with the American PI than with the Zulu speaking research assistant. There was a noticeable difference in the answers that were given to the Zulu-speaking research assistant present, suggesting perhaps a social desirability bias related to the older age of the research assistant or to the longstanding relationship that the research assistant has with the participants.

The interview guides were found to be sufficient for the purposes of the study, culturally appropriate, and understood by the participants. Because methodology was the only major change from the pilot to the data collection phase, pilot interviews that were of the same methodology used in the study (1-on-1 with PI) were included in the data analysis.

All semi-structured in-depth interviews were conducted in English and varied in length between 45 minutes and two hours. While participants were comfortable conveying their thoughts and ideas in English, they were encouraged to openly express themselves in another language if necessary or appropriate. A range of topics were discussed including sources of health information, perceptions of current health services, and opinions on alternative health services. For example, “If you wake up and are not feeling your best, what do you do?” and “Can you describe your experience at the local clinic?”

Rapport was built by conversing in small talk prior to the interview. Conversation about the participant’s day and the weather continued until the participant’s body

language suggested that they were starting to relax (approximately 5-10 minutes). The interview guide was on the table during the interviews, but was not referred to while the interview was being conducted. It was found that referring to the interview guide or taking notes broke rapport between the interviewer and participant. As a result, the PIs memorized the topics of interest and followed the lead of the participant to facilitate an open and comprehensive discussion.

3.3 Data Analysis

All interviews were recorded and transcribed verbatim. Data were read independently and codebooks were developed by the two PIs based on arising themes. Codes were developed inductively and deductively through modified grounded theory (as described by Borgatti; Glaser and Strauss 1967[38]; Strauss and Corbin 1990[39]). The two codebooks were then synthesized and consolidated and code definitions were agreed on by both PIs.

Interviews were coded independently, merged, and recoded to encompass both of the PIs' coded segments. Inter-coder reliability was checked for three interviews and discrepancies were discussed. Memos were additionally used to capture thoughts and associations not captured by the codes. Data were coded and analyzed using MAXQDA10 Qualitative Analysis Software.

3.4 Strengths and Limitations

This study utilized the BT20 cohort, which has been studied regularly for over 20 years, exposing participants to more regular screenings and health education than the general population of young people. This may have impacted answers related to

knowledge of healthy behaviors and expectations of health services. Additionally, all participants were aged 21 or 22 at the time of the interview. While this falls in the age range of “young people” (aged 10-24), it falls in the upper limit and might not be representative of younger persons perceptions. Lastly, the data in this study may be subject to contextual effects that may affect data quality. This may include characteristics of the interviewer, differences in reactions to each PI interviewing, level of comfort with the interview process, and setting. Efforts were made to minimize these effects, through rapport building, the informed consent process, and controlling behavior and dress among the PIs.

Nonetheless, this study gave young people the opportunity to share their experiences and opinions on health services in an open-ended context using their own words. This is particularly important, as many themes that arose might not be appropriate for the format of a semi-structured interview or closed-format survey. That said, data provided by this study can inform future qualitative and quantitative research regarding young people’s knowledge and experiences of health services in Soweto to the extent that the respondents are representative of large segments of Soweto youth.

Chapter 4: Results & Discussion

A total of 25 interviews were conducted (including pilot interviews), 23 (14 female, 9 male) of which were used for data analysis. Interviews captured perceptions and opinions for both recent users and non-users of local health services (15 users/ 8 non-users). Data were coded and analyzed according to modified grounded theory.

The current study specifically examined the knowledge of YFS initiatives, perceptions of current health services, and opinions on alternative health interventions for future implementation. This chapter will explore and summarize the main findings from each of these domains to provide a greater understanding of young people's perspectives on the state of the health system in South Africa.

4.1 Knowledge of YFS Initiatives

Overall, knowledge of YFS programs was very low; of 23 participants interviewed, only 3 reported ever hearing about 'youth-friendly services.' For participants who indicated they had heard of the program, when asked to describe what they knew of the program, no participant was able to express deep knowledge of the program's purpose or activities.

Participants were provided with a brief description of the program and asked what they thought about it. After describing the purpose of YFS, some participants acknowledged these services might exist but recognized the lack of knowledge as a problem. A few of the participants particularly noted that there should be more advertisement and publicity for greater awareness.

"I think the services are ok, they're enough. The only thing is: are youth attending them? You know, going and learning about them? The youngsters, they need to be more, um, what can I say, they need to be made aware *of that, that these services are there for us to go. Not just to be there only, but for us to go and learn." (Female)*

"I think there is one at our clinic, but I've never been to that… I've never heard people say, speaking anything about or going there. Yeah, like cause sometimes they don't know about it. It's just there's a center there, people don't really know what's going on... they're not really clued in on what's going on."(Female)

For those that did not report having knowledge or experience with it, YFS was presented as a hypothetical situation. Most participants agreed that it would be a good program, and that nurses should be trained on proper sensitivities to young people's needs. Most also stated that younger nurses would help, as they would be closer in age to the participants and understand their needs better. Additionally, youth might feel more comfortable confiding in younger nurses as they view older nurses as being more likely to judge them. Respect, confidentiality, and dedication were repeated characteristics participants would like to see displayed by YFS nurses. What is most reflective of current and historical attitudes towards services is that participants highlighted that respect and equity should go out to all patients regardless of their situation.

"They must be committed to their job, treat everyone equally. Yeah, I can say I'd like that." (Male)

"Train them to respect other persons. That comes most of the time… everything comes respect. Respect… taking someone up who is young teens, old teens, nothing to you… you don't have to discriminate people." (Male)

For the most part, sexual health was the main concern of those interviewed. This includes issues related to STIs, HIV/AIDS, and pregnancy. Additionally, general health education, sugar diabetes, and counseling were brought up as important health issues facing these young people. Some also went on to talk about the need for additional recreational activities that potentially YFS could provide including sports, dance, and art.

Participants were then asked if they had ever heard of the loveLife groundBREAKERS program with which NAFCI and YFS was associated. Overwhelmingly, 18 of the 23 participants indicated that they had heard of groundBREAKERS. When asked then to describe what the program was, 14 of the 18 participants were able to correctly match a description to the program - indicating they were people who talked about health in the community and provided information about health issues. While not everyone was able to identify them as "peers," there was a strong sense of trust in the program and the information they provided. The majority of people who had heard of groundBREAKERS had experience with their services - either directly with the groundBREAKERS themselves, or with the pamphlets and brochures they distribute. Overall, participants felt positively towards the groundBREAKERS programs, and found them to be good for health education and outreach.

"They came to our school there, and gave us some books. So we were chilling on the corner of class, late we stay in the corner and they came and opened the book.

And my friend 'hey, hey did you see that?' 'Yeah, yeah' We just talk there at the corner, open a conversation. Yeah, it could help more people, these books. One person can change our eyes."(Male)

"They used to come and be in school when I was studying. Yeah, they were gonna teach us about HIV and AIDS. About sex, about our health, about a lot of things that will keep you safe. And even like, when the schools are closed, come at the shebeens ,and talk to the kids. Yeah, and give us magazines… They helped a lot because of their stories, they're people like us. Tell you, that help you break through, and then you learn from them. Like, if this person can break through, maybe you can also." (Female)

4.2 Perception of Current Health Services

Analysis of data reveals that young people are generally dissatisfied with the current health services in Soweto. While there were many specific reasons related to individual's particular experiences, several themes arose among those interviewed that are worth noting. Dissatisfaction was related to a variety of factors including a lack of resources, long waiting times, and poor quality of care. These reflect well-documented barriers to acceptable health care services[14, 15].

Most young people interviewed did not report experience with or confidence in local health clinics having the appropriate resources to meet their needs. While staffing shortages were reported, insufficient diagnostic equipment (such as x-rays) and medical stocks were most discussed. Because of these frequent drug stock-outs, clinics can often

only offer basic medications such as antibiotics or generic painkillers like Panado© which are readily available at small tuck shops and supermarkets. This leaves participants feeling like going to a clinic is an unnecessary extra step that does not always result in better medication or opportunities.

> *"They'll give you Panado©. Any pain killer or they'll just say they're out of stock. So you might as well just buy your own pain killer and not go to the clinic because, you know when you go to the clinic and you have a rash they'll just give you calamine lotion. So you might as well just buy it yourself without even going there. It's just easier, because you already know what they're going to give you. So you might just buy it." (Male)*

For those that did visit local clinics, they often faced extensive wait times in long queues. Most young people interviewed reported waiting anywhere between 30 minutes and several hours to see a nurse or doctor. One patient reported having to arrive to the clinic at 6:00 in the morning in order to be seen by someone before the clinic closed at the end of the day. Others reported rejection from the clinic if you didn't arrive by a certain time and early closures. This discontent was aggravated by a perception that their wait was often a result of nurses taking prolonged tea-breaks, leaving early, or dismissing their duties. Overall, participants felt nurses were rude, did not establish a sense of confidentiality, nor show respect to their needs and considerations. Some went on to differentiate this behavior from doctors, indicating that while doctors were scarce they found them to be more attentive to the patients and committed to their jobs.

These causal conditions in dissatisfaction were heightened by an underlying lack of choice and palpable inequity in access to quality services. When participants discussed

perceptions of health services, including their own experiences, many asserted feeling they had a lack of agency regarding the services they could use. This was expressed as a lack of access to "*better*" private services due primarily to financial constraints, as well as to "*good*" public services due to geographic policy.

Participants described a distinct variability and hierarchy of services, insomuch that they were able to compare and contrast each level of this hierarchy. Most referred to a "you get what you pay for" attitude towards the services. Unanimously, private clinics were viewed as the pinnacle of health care services. They were described as clean, fast, reliable, and better staffed and stocked. There was also generally a greater trust in the information and diagnosis given at a private clinic by doctors than at public clinics by nursing staff. For those that had accessed these services (6 interviewees), they indicated not only satisfaction with the services, but gratefulness in their ability to pay for them and avoid the public system.

Below private health services were chemists or pharmacists, who can do quick diagnosis and prescribe over-the-counter (OTC) drugs and general medications. For the most part, these services allow patients to bypass clinics and obtain standard prescriptions if they can pay for them. Dependency on these types of services may be partially driven by the unreliability of public health services having the appropriate medication, as previously mentioned.

When either of these services is inaccessible due to financial barriers, young people had to rely on free public services. Several participants talked about the variations between public clinics; some neighborhood clinics were regarded as "*good*" while others were "*bad*." "*Good*" public clinics, as mentioned above, were those that were regarded as

having greater resources, shorter waiting times, and friendlier staff. Lower-resourced, heavily-burdened, unfriendly local clinics were regarded as "*bad*" clinics.

This social hierarchy of health services echoes the institutionalized hierarchy of apartheid. While there are no longer formalized structures in place preventing certain races from accessing certain services, the residual economic disparities continue to perpetuate these barriers. However, legislation intended to better distribute resources and ensure equitable access to services by preventing people from over burdening one clinic over another by forcing them to visit their nearest clinic may in fact create less choice and greater inequity to quality services. To deal with these barriers, participants had several action strategies that can be grouped into three themes: avoidance, fatalistic acceptance, and manipulation of the system.

When not feeling well, patients reported waiting until it became "serious" to address illness. Those interviewed primarily relied upon home remedies or information gained from libraries or the internet. Many reported using mobile sites such as *Google* to research health and health education. This became even truer in regards to sexual and reproductive health questions. Online chat rooms were reported by a couple of participants as a source to ask anonymous questions and get multiple perspectives on an issue. Participants did recognize that these services were not always reliable and they had to weigh the responses and choose the "best" one.

When illness did worsen, young people indicated that oftentimes they would by-pass primary care facilities for services perceived as more reliable, such as hospital services. Participants found self-treatment with home remedies, OTC drugs, or direct

prescriptions from pharmacists to be the best method of getting necessary medications rather than relying on clinics which often face drug stock-outs.

"Cause some—they do go to the clinic but then, like I said, the other problem is that you find people who are judgmental or rude. You know? So that's the reason why they are afraid to go. They'd rather just go to the library and read books about it and just inform themselves about it." (Female)

For those that could not afford private services, reliance on the public health system oftentimes only came after all other treatments and home remedies failed. The attitude towards going to health services was often that of a fatalistic acceptance in having to face long lines, poor treatment, and the risk of being turned away.

"Interviewer: At what point would you think about going to the clinic?

Participant: When it is serious. But I don't like clinics so I don't usually go.

Interviewer: What makes it serious?

Participant: When you have taken all other methods and they don't help… you must go."(Female)

"Ah, it's it's it's quite bad. Some people don't even have the money to go to private doctors, so they have no choice. They they have to go there, and be in the queue for long hours. It's not it's not good." (Female)

One last strategy for dealing with “bad” clinics was simply to seek out better clinics. Unfortunately, due to National Department of Health policy that patients must visit their nearest clinic first and get subsequent referrals if the patient would like to go elsewhere, this is not as easy as just arriving at a preferred clinic and being seen by a staff member. Several participants discussed manipulating the system by falsifying their admitting papers by putting local addresses or using other family member’s information.

> *Participant: Well… there are some good clinics, the public clinics, there are some, but eh… these days they’re strict at clinics. They’ll check your address so you can’t go to any clinic you want. Cause then you want to go to the favorite clinic, so they get packed there and other clinics are empty. So now they first check your address before attending you.*
>
> *Interviewer: How do you feel about that?*
>
> *Participant: No… it’s bad. Because we go there knowing we get the better service than the other clinics. But we can’t go… unless I change my address. (Female)*

These structural limitations on choice reflect those seen just twenty years earlier. This health service hierarchy is a remnant of the strongly enforced hierarchy imposed during the apartheid era. This is the same era that institutionalized unequal distribution in social service capacities that has crippled the ability of certain areas to properly manage resources. While patients cry out for equity in choice and access to quality services, the system itself continues to perpetuate these disparities through legislation and staff attitudes. Some participants discussed being gossiped about, judged, or even turned away if they were perceived to have the ability to afford private services. They were told they

were trying to "*take advantage*" of free services that are not "*meant for them*." Others discussed feeling that if clinic workers judged them to be of a lower class, they treated them as if they were deserving of poor services and treatment.

When faced with this type of treatment, young people felt they did not have the social capital to make complaints or demand better service because the services were free. In one way or another, many young people were able to validate receiving poor service because it was a service intended for those who couldn't afford "good" services in the private sector. One patient went on to discuss how this perpetuates poor treatment from the nursing staff because they will not be held accountable for their behavior.

> *"The one in [neighborhood 1], like, there are nurses who are treating white people, colours, like there are all types of people who are going there. So I think maybe first that the advantages is that you have people who treat people good because they know there are other people who will generate results. When they are treated bad, the report it right away. So I feel like they should always treat us like people. [At neighborhood 2], they take advantage. There are only black people there. They take advantage of that… they just mistreat people because they are at the local." (Female)*

The following case study highlights each of these strategies and the underlying classism that still permeates the health care system.

Case Study

A 21-year-old male lives in a particular neighborhood in Soweto. He lives with his mother, younger brother, and older sister's daughter. He spends most the day hanging out with his friends, chatting about life and playing soccer. On weekends he enjoys drinking with his younger brother and friends at the nearby bar. He doesn't often seek out advice, but would rather like to sit back and take in information about life and health through observation. About a year ago, he suffered from a severe tooth ache. After ignoring the pain for several days, he sought out advice from his mother who prescribed a home remedy.

> *"Like when I was sleeping at nights, yeah at nights it was so painful too much like it could kill you. You just woke up my parents you say 'mom, look I can't go to sleep.' She say, 'go there to the toilet, take some Colgate [rubs finger over tooth/gums], ok just go to sleep.' Maybe I'm just turning when I'm sleeping or turn to the side, 'ah shit, pain, MOM!' It's just calling my mom and man my tooth you know what? You know some tooth, the hurting will kill you, so you must take the tooth [out], you could die with that pain."*

When he woke every morning the pain lessened and he went on with his day. At night the pain would return, but he would continue to rub toothpaste on it hoping to avoid the clinic the next day. This went on for several months, cycling through the pain every day and night until he decided to seek medical attention.

Knowing that the clinic nearest him did not have dental services, he went to a different clinic for the extraction. When he arrived, he received negative commentary from some of the nurses regarding the gold fillings he had in his teeth.

> *"I'm just in the clinic, when I'm there I just do that outside and then pay, but I can hear them discuss… Ah 'he puts gold in his teeth, so why is he here right now at the clinic just pull his teeth? Why doesn't he go outside and pay for private?' That's why they say. They just talk. I don't care, I need to pull my teeth."*

Despite this, he registered his name to be treated, but was denied treatment because he visited a clinic that was not the clinic nearest to him and did not get an appropriate referral. They told him he had to return to the other clinic and then come back. Because this would take extra time and money he simply did not have, he chose another solution:

> *"You have to go away for that… yeah so you just go there and just write my name and the new address where I'll stay at that moment in that village. So just write there and they'll say 'ok, fine, let's pull your teeth."*

This young man exemplified many of the barriers young people face in the current structure of the health system. Because of his fears and mistrust in the health system, he avoided the services until the pain of his condition became unbearable. At this point he took on a fatalistic realization that he would have to go and get the tooth extracted. Although he could not afford private services, he sought out an appropriate and preferable public clinic. Because of both institutional policies and judgment from the staff, accessing services at this particular clinic proved difficult. The only way to get the service he needed was to manipulate the system and endure undue judgment from those meant to help him.

4.3 Attitudes toward Alternative Health Services

Participants who had not heard of YFS were asked to reflect on a short description of the program and give their opinions on it as a hypothetical. The results of this have already been discussed in a previous section. This study also examined the opinions of two alternative services: School Based Health Clinics (SBHC) and Community Health Workers (CHW).

Overall, there was no particular service that was preferred over another (8 YFS, 6 SBHC, 9 CHW). Most of the participants were excited to discuss these potential services and enjoyed the practice of visualizing them overall. They did seem skeptical, however about the likelihood of these services being implemented and implemented well in Soweto - potentially reflecting the general feeling of disenfranchisement with current health service interventions.

School Based Health Clinics

Overall, reactions to School Based Health Clinics were positive. Nearly all the young people interviewed (22 interviewees) said they would have liked to have had a SBHC at their school when they were younger. Those interviewed mentioned several reasons they would like to see something like SBHC at the schools in Soweto. One reason was that students would be able to access immediate care for things such as illness and injury. Boys tended to bring up this reason most due to an increase in fighting and violence they've seen. Because these services would be available immediately, students would miss fewer class hours to visit services outside the school grounds. Because of this, some students discussed the overall benefits in learning and success that might come from having services available at school.

Additionally, several participants alluded to a greater awareness of healthy lifestyles that might come from having a clinic within the school grounds. They discussed how clinics could conduct health education sessions during the breaks or run open classes on sexual health, healthy foods, and exercise for a healthier lifestyle. Teachers could collaborate with SBHC staff to provide education and counseling referrals.

There was little consensus regarding the demographic characteristics (age, gender) of potential SBHC staff. The main theme that was clear was that SBHC be staffed by independent nurses not affiliated with the school. Several of those interviewed showed uneasiness with the idea of teachers learning about the health concerns of their students that they might not respect confidentiality.

Some concerns that arose related to the deep sense of equity already discussed. Participants were concerned that if these services were in schools they would then only be available to current students. These services, then, would not be available to out-of-school youth or young adults that are no longer school-aged. Some also discussed concern for older-aged people being excluded from these services, and perhaps more outreach services should be available to them.

Community Health Workers

In general, the Community Health Worker model most corresponded with the feeling for greater equity in access to health services. Participants liked the idea of having health services visit them in their environment, but on one condition: they visit all houses. It was widely agreed that if CHW do conduct home visits, they should not target certain houses or skip houses. Part of this was a concern for confidentiality and stigma - if a CHW visited a patient's house, neighbors might wonder what is happening at that house

and what is wrong. What came up most, however, was the sense that if CHWs only targeted and visited certain houses, they might miss households which have need but who cannot seek out their services.

> *"For example, they go to this house and maybe from this house you're skipping this one and going to that one [points to three imaginary houses]. What if this person would die today? [pointing to skipped house] If I did come it would be fine and I would be seeing he would be having sickness."(Male)*

This sentiment was particularly held true among young people in regards to caring for older generations. Many participants discussed concerns for older people, as they have limited mobility but increased health needs. This might stem from the fact that many of these participants live with their grandparents or report being very close to their grandparents. Many take care of them on a day-to-day basis, and so meeting the needs of older people is as personal a matter as meeting the needs of young people.

Health education and HIV/AIDS testing were among the services participants would most like to see offered by CHWs. Other services that were discussed included general check-ups and assessments for obesity, blood pressure, sugar diabetes, and illness. A few participants also discussed the potential for CHWs to hold community gatherings for health education and promotion - such as mass screenings, and "health parties" where music was played and brochures and pamphlets could be distributed on health and health services nearby.

There was little consensus regarding the demographic characteristics (age, gender) of potential CHWs. The main theme that arose was that CHWs were clearly

identifiable (with a uniform or badge) so that safety could be ensured. Some interviewees seemed hesitant to have strangers visit their homes, particularly women, for fear of being victimized but stated that it would help if there was a way to identify them as being CHWs.

Chapter 5: Conclusions and Implications

The data reported and discussed in the previous chapter were presented in regards to the knowledge of YFS and associated programs, perceptions of health services, and attitudes towards alternative health services. The following chapter will discuss conclusions drawn from this data as well as implications for implementation and future research.

5.1 Knowledge of YFS Initiatives

Among those interviewed, there was no practical knowledge of Youth Friendly Services (YFS). Lack of awareness of YFS has two underlying potential causes: (1) the clinics used by our participants do not implement or enforce YFS standards or (2) the clinics do adhere to YFS standards, but young people do not recognize this as anything more than good practice. If it is the former, immediate and full implementation of YFS standards is recommended in all local clinics according to the 2012 National Adolescents and Youth Friendly Health Services Strategy[4]. Greater monitoring of these clinics should also be established to ensure YFS initiatives are being implemented properly and to standard.

If it is the latter, greater efforts should be made to publicize YFS services in the clinics in which they are available including, but not limited to: media campaigns, branding, and clear signage around the clinics. Furthermore, because there is substantial knowledge and positive perceptions of loveLife and the groundBREAKERS programs, it might be beneficial for YFS programs to utilize similar outreach and communications approaches to increase knowledge of services in the communities. While groundBREAKERS is more likely to target a younger audience, participants in this study

reported positive experiences with outreach programs, and substantial information gains from peer educators. It is recommended that similar peer-educator programs be developed for outreach into the community separate from services offered in the clinics.

5.2 Perceptions of Current Health Services

Improvement in and advertisement of the youth-friendliness of the centers is limited by the general dissatisfaction young people have for public health services as a whole. The reasons for this dissatisfaction reflect those seen in literature namely- availability, accessibility, and acceptability. What is particularly interesting is that negative perceptions stemmed primarily from interactions with service staff and availability of resources rather than the condition or accessibility of facilities. In general, people and supplies were more important than clinic structures. Understanding this priority will help to shape public policy in particular for YFS and the National Adolescent and Youth Friendly Health Services Strategy by recognizing more resources should be invested in proper training of staff and ensuring adequate stock supplies over renovating clinics.

While acceptability of available services was reported to be a barrier in utilization, upon deeper analysis, there seemed to be underlying feelings of inequity in choice and access to more acceptable services. Participants reported feeling that the services that were available to them were of lower quality because they were free and intended for those of lower SES. While this can potentially be a natural result of relational disparity- feeling like what you have is worse than it is because you perceive what you don't have is better than it is, this perception can also stem from policies established in the Apartheid era. Greater, more intentional research should be done to

investigate the legacy of apartheid on the experiences with and perceptions of health services and potential strategies to ease this influence.

A limit on choice was also discussed in regards to policy requiring individuals to utilize the clinic nearest them, regardless of its quality or available services. Current enforcement of this policy might indeed lead to greater restrictions on freedoms and widen the inequities in health access/outcomes. Because of this, legislation regarding geographic limitations to access (in order to improve resource allocation) should be reevaluated and a full policy analysis is suggested. Within the clinics, in-service training of nurses should be prioritized for all clinics without prejudice. Training should follow the strategy laid out by the Department of Health with a continued focus on sensitivity to young people with emphasis on equitable treatment to all.

5.3 Attitudes towards Alternative Services

When presented with alternative health services, young people displayed no overall preference- responses were relatively evenly distributed among each option described in the interview (YFS, SBHC, CHW). Because there were no clearly preferred services, further examination should be conducted on these alternatives including their cultural-appropriateness, logistic feasibility, and cost-benefit analyses before adopting a new health system program.

Reflective of the Erlukar study, participants did not preference any particular demographic (age, gender) for service providers. Attitude and morale of service workers was the most influential factor participants would like to see improved. This indicates that scouting out and recruiting certain people to be health workers is less important than improving the training and attitudes of those that are already there. Furthermore, equity

continued to be a driving theme among the discussion of alternative services. This indicates that an emphasis on equitable treatment towards all should be integrated into these trainings.

5.4 Summary of Recommendations

As discussed, there are several implications and recommendations for future work that stem from the current research. These can be summarized as follows:

- More rigorous evaluation should be carried out of whether and to what extent local clinics in Soweto, South Africa are implementing YFS standards.
- More effort should be made to publicize the purpose and standards expected of YFS initiatives and erect signs that indicate where YFS clinics exist. This would have two purposes- to alert young people of clinics that might suit their needs better, and keep nurses and clinic staff accountable to the advertised standards.
- Peer-education programs should continue to be supported and grow, but this might be better facilitated through NGOs or non-profits, rather than already resource strained clinics.
- Legislation regarding geographic-limitations to access and utilization of local clinics should undergo a formal policy analysis and re-evaluation.
- Nurses and clinic staff should receive in-service training on appropriate treatment of patients (including confidentiality, sensitivity, and friendliness) with an emphasis on equity and equality for all.
- Further research should be conducted on the lingering effects of Apartheid on attitudes, perceptions, and experiences with health services in South Africa and how this might impact service access and utilization.

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Appendix A: In-depth Interview Guide

Young people's perception of a Youth Friendly Services in South Africa

Site: ____________________________________
Interviewer: ______________________________
Date: ____________________________________
Start time: _______________________________
End time: ________________________________

Interview Guide

Good day, and thank you for agreeing to this interview today. My name is _______________, and I am part of the Birth to Twenty research team here in Soweto. As you know, we have been collecting information on health access and utilization among youth here in Soweto. Today, I would like to interview you specifically on your perception and feelings about these services. The aim of this study is to better understand how you experience health services in this area. I will be asking you questions about your life to hear about your personal experiences and opinions on the issues we discuss.

((TAKE CONSENT))

Thank you for your consent. I want to remind you that participation in this interview is completely voluntary and if you do not feel comfortable answering any questions or would like to stop at any time, please don't hesitate to let me know. Additionally, if you feel you would be more comfortable or could better express yourself in a language other than English, feel free to do so.

Is it alright if I turn on the recorder now?

((TURN ON RECORDER))

Do you have any other questions before we begin?

A. *Introduction*

Great! I am excited to speak with you today! I want to get to know you better, so I want to talk to you first about you and your friends and family, but would like you to bring up any ideas of topics you feel are related. I am very interested in your ideas and experiences and appreciate you meeting me.

1. I want to know what a day is like for you. So let's start with when you wake up. What do you do when you wake up?

   Probes: Then what do you do? Who do you see? Who do you stay with? What do you enjoy doing on weekends? Who do you enjoy spending time with? (*probe on whatever they talk about. I.e.: school/work/shopping/activities*)

B. *Support Network*

2. Can you describe the relationship you have with your family.

   Probes: How has this changed from when you were younger? Do you go to your family for advice? What kind of advice do you ask? Can you tell me about a time when you specifically asked for their advice? Does anyone in your family come to you for advice? What things do you talk about?

3. Can you tell me about the friendships in your life.

   Probes: Can you describe the relationship you have with your friends (how long has the friendship been/how close are you)? Anyone else? (keep probing until they say no) Do you go to your friends for advice? What kind of advice do you ask? Can you tell me about a time when you specifically asked for their advice? Do your friends come to you for advice? What things do you talk about?

4. Are you romantically involved with anyone?

   Probes: Can you talk about them? Can you describe the relation you have with this person? Anyone else? (keep probing until they say no) Do you go to this person for advice? What kind of advice do you ask? Can you tell me about a time when you specifically asked for their advice?

5. Are there other groups or people that you interact with?

   Probes: Can you describe the relationship you have with the people you interact within those groups? Are there any other groups that you interact with? (continue to ask and probe until no) Do you go to these people for advice? What kind of advice do you ask? Can you tell me about a time when you specifically asked for their advice?

6. Can you draw me a picture of the people/relationships in your life?

   Probe: Who would you talk to for advice about your health? Why? Why not? Can you tell me about a time when you specifically asked for their

advice about your health? Why would you go to this person but not this person?

C. *Healthy living*

7. Where do you think **other** people learn about their health?

   Probes: What do these people/sources say about being healthy? What do you think people can do to stay healthy? Where do **you** learn about staying healthy? Is there any other place? What do you do if you have a question about health?

8. What do you do if you wake up and you are not feeling well?

   Probes: Do you talk to someone about it? Who do you talk to first (Why)? Why not *one of other people mentioned*? Where do you go if they didn't answer your questions? What do you do if it does not get better/continues?

9. Where do you learn about sexual health (e.g.: HIV/STIs/condoms/pregnancy/ pregnancy prevention)?

   Probes: Is there any other place? What do you do if you have a question about your sexual health? What would you do if you were worried about your sexual health? Who would you talk to about it? Who would you talk to first (Why)? Why not *one of the other people mentioned?* Where would you go if they didn't answer your questions?

D. *Experience with Health Facilities*

10. What have you heard about the local clinics?

    Probes: How do **other** people describe the care they get there? What are the types of services there? What do people say about the waiting time? How do people describe the place (location, clean, space for privacy)? What do people say about the people who work there?

Thank you for your responses so far. I want to ask you a little more about **your** experience with the local clinics now.

11. Have you been to a local clinic in the last six months?

    (if no) Was there a time in the last six months you did not feel well? Have you sought treatment from another place or person (chemist, private doctor, sangoma)? Why did you choose to seek treatment from them? (**if no to both of these first two questions, go to question 13**) What were some reasons you decided not go to the clinic? Did you talk to anyone about going to the clinic? If so, who? What was their reaction? (**Go to question 13**)

    (if yes) How many times did you go (For each of those times, why did you go?) Can you talk about the last time you went? What did you go for that

time? Which clinic did you go to? (*If for illness:* Did you go as soon as you started feeling unwell (why/why not)?) Why did you go to that clinic? How did you get to the clinic (Can you describe what it was like to get there)? Did you talk to anyone about going to the clinic? If so, who? What was their reaction? Did you go with anyone to the clinic (Who? Why did you go with that person?)?

12. Can you describe for me what it was like when you were at the clinic?
    Probes: Can you describe for me the care you got there? How much did it cost? How long did you wait to be seen by a sister/nurse/healthcare worker? If you had a similar problem again, would you go back? Why/why not?

13. What do you think would make young people more likely to use local clinics?

Youth Friendly Services

So as I said, we're looking to improve health services for people your age. There have been some suggestions about how to do this but I wanted to get your opinion on these ideas.

14. Have you heard of something called Youth Friendly Services?

    (**if no**) Have you heard of loveLife groundBREAKERS? Can you tell me what you know about them? Have you had any interaction with a groundbreaker (if so what/describe?)? How did you feel about your experience with the groundBREAKER? **(go to question 16)**

    (**if yes or unsure**) Tell me what you know about Youth Friendly Services (YFS). What would you say are some of the similarities between YFS clinics and other clinics? What are some of the differences? How do you feel about the differences between the two types of clinics? Which clinic type would you prefer to go to? Why?

15. Have you ever used a Youth Friendly Services clinic? (**if no, go to question 16**)
    Probes: Can you describe your experience there? Can you describe the place (location, clean, space for privacy)? How did the doctors/sister/nurses treat you? How did you feel about the Youth Friendly Services while you were there? Why? Do you feel like the services were friendly towards youth? Why/why not?

16. Great! So Youth Friendly Services is a program where nurses are specifically trained to work with young people to provide services for their specific needs within the local clinics. What do you think a Youth Friendly Services clinic should be like?
    Probes: Which services do you think Youth Friendly Services clinics should provide (Health education, reproductive health, check BP, diabetes,

social work/counseling, general health/illness)? Do you think there would be any advantages to having Youth Friendly Services? Would there be anything you would be concerned about? What do you think could be done to limit these concerns?

E. Alternatives/Solutions/Closing

17. Another idea is School-Based Health Clinics that are clinics that are set up on school premises. Are you in school now?

    (if no) Thinking back to when you were in school, how do you think you would have felt about having a School-Based Health Clinic at your school? Why? What do you think a School-Based clinic should be like? Which services do you think School-Based Health Clinics should provide (Health education, reproductive health, check BP, diabetes, social work/counseling, general health/illness)? Do you think there would be any advantages to having a clinic on the school premises? Would there be anything you would be concerned about? What do you think could be done to limit these concerns?

    (if yes) How would you feel about having a School-Based Health Clinic at your school now? Why? What do you think a School-Based clinic should be like? Which services do you think School-Based Health Clinics should provide (Health education, reproductive health, check BP, diabetes, general health/illness)? Do you think there would be any advantages to having a clinic on the school premises? Would there be anything you would be concerned about? What do you think could be done to limit these concerns?

18. So we've talked about improving services in the clinics, how do you think young people would feel if they could access health services outside of a clinic?
    Probes: Which services do you think young people would want to be provided outside of the clinics (e.g.: Health education, reproductive health, check BP, diabetes, social work/counseling, general health/illness)? Which ones would **you** want available to **you**? Where should they be provided (Why)?

19. How would you feel about Community Health Workers coming to your **home** to provide the services you need rather than at the clinic?
    Probes: What do you think a Community Health Worker should be like? Which services do you think Community Health Workers should provide (Health education, reproductive health, check BP, diabetes, social work/counseling, general health/illness)? Do you think there would be any advantages to having Community Health Workers visit your home?

Would there be anything you would be concerned about? What do you think could be done to limit these concerns?

20. So from the ideas we've talked about- Youth Friendly Services, School-Based Health Clinics, and Community Health Workers- Which of these three options do you think would work best in Soweto?
    Probes: Why? Which of these three options do you think **you** would prefer to use? Why?

21. If you were the Minister of Health, what would you do to improve health services for young people in this area?
    Probes: What do you think would make young people feel more comfortable? In your opinion, what do you think would make it easier to use services? What would you do to improve young people's **knowledge** about their health?

22. What advice would you give to young people about using the local clinics?

23. Are there other factors that affect young people seeking medical care in Soweto you feel are important that we have not discussed?

24. Do you have any questions for me?

Thank you so much for your participation today!

Appendix B: Participant Recruitment Call Script

Participant Call Script

Young people's perception of a Youth Friendly Services intervention in South Africa

Hello, my name is _______________ and I am part of the Birth to Twenty research team in Soweto. We're calling to firstly thank you for your recent participation in the health access survey. We would like to hear more about **your** personal perceptions and experiences with health services. We are hoping to better improve health services for young people in Soweto, and your opinion is very valuable to us.

We would ask you some questions that would not take more than 1 hour. You will be compensated for transport, and refreshments will be provided. Participation is voluntary and all information will be kept confidential. Do you have any questions?

Would you be interested in coming to Bara to participate in this study?

If you would like some time to think about it or have any questions before the interview, please contact Brittany Schriver or Kate Meagley on 079 366 3373. You can also contact the Birth to Twenty Cohort offices at The University of the Witwatersrand on 011 933 1122.

Appendix C: Informed Consent Sheets

Participant Information Sheet

Young people's perception of a Youth Friendly Services intervention in South Africa

Hello, my name is _______________ and I am part of the Birth to Twenty research team in Soweto. As you know, we have been collecting information on health access and utilization among youth here in Soweto. Today, I would like to interview you specifically on your perception and feelings about these services. The aim of this study is to better understand how you experience health services in this area.

Why are we doing this study?

We know that a healthy lifestyle begun in adolescence may help improve the future health of adolescents and their children. Health services play a key role in this and to support the development and implementation of interventions to improve adolescent health it would be really helpful to understand how you, as a young person, experience health services in the area.

What would taking part involve?

If you agree to take part I would ask you some questions that would not take more than 1 hour. I will take notes when we talk but I would also like to record our conversation to help me remember what you said and because I might not be able to keep up with my note taking. Recordings will be digitally recorded and the files will be downloaded and kept in a password-protected file on a password-protected computer. Only members of the Birth to Twenty research team will have access to these files which will be stored securely. You can indicate whether or not you are happy for me to record our interview on the consent sheet.

Are there any risks and does it cost anything to take part?

We don't anticipate that there will be any risks involved in taking part in this study. It does not cost anything to take part in this study. We will be asking some questions that might be sensitive. If you would like additional counseling, a referral can be made for you.

Are there any benefits?

In taking part in this study you would be helping us to find out how adolescents experience health services in this area. This information could be very interesting to the Department of Health. It will also help us to improve the health of adolescents in this area. You will be given a snack and cool drink during the interview. At the end of the interview before you go home, you will be given R50 for transport.

What if I don't want to take part, or if I change my mind?

Participation in this study is voluntary. You may refuse to participate, or withdraw your consent to participate, at any time during the study without any penalty or loss of benefits.

Will my details be kept confidential?

All your details will be kept confidential except where we are required to disclose them by law. Your name will never be recorded during the interview. Only the researchers in the team will have access to your interview and results, and these will be stored securely. This study protocol has been submitted to the University of Witwatersrand, Human Research Ethics Committee (HREC), and written approval has been granted by that committee.

What will happen to the results of the study?

The results from this study will be presented to the Department of Health and may be published in academic journals. However, any publication of results will not identify participants. In some cases we might like to use quotes from out interviews but these will never identify participants by

name. You can indicate whether or not you would be happy for me to use quotes on the next page. I commit to making the results of my study available to you as soon as they are available.

What if I have any questions?

If you have any questions please contact Brittany Schriver, Kate Meagley or Professor Shane Norris on 011 933 1122. You can also contact the Human Research Ethics Committee of The University of the Witwatersrand if you have any questions or concerns about the ethics or the conduct of the study.

YOU WILL HAVE A COPY OF THIS INFORMATION SHEET TO KEEP.

If you are interested in taking part in this study please read and sign the following consent form.

Thank you for your time,

Informed Consent Sheet

Before you decide whether to sign this form please make sure of the following:

• You have read this consent form, or someone has read it to you
• The study has been explained to you
• You have had all your questions answered
• You understand you can ask more questions at any time
• You understand your clinic's study records will be available to the study team but that they will be kept confidential

I ___________________________ confirm that I have been informed about the study "Young people's perception of a Youth Friendly Services intervention in South Africa" and that I understand what participating in this study would involve. I hereby give my consent to participate in this study:

☐ Yes, I give my consent to participate in this study

☐ No, I do not give my consent to participate in this study

☐ Yes, I give my consent for quotes from my interview, that will NOT have my name attached to them, to be used in publication of the results of this study

☐ No, I do not give my consent quotes from my interview, that will NOT have my name attached to them, to be used in publication of the results of this study

☐ Yes, I give permission for the interview to be recorded

☐ No, I do not give permission for the interview to be recorded

PARTICIPANT:

Printed Name **Signature** **Date**

RESEARCH ASSISTANT:

Printed Name **Signature** **Date**

Appendix D: IRB Exemption Letter

5 June, 2012

RE: Determination: No IRB Review Required
58317- Title: Young people's perception of a Youth Friendly Services intervention in South Africa: A qualitative investigation
PI: Brittany Schriver

Dear Brittany Schriver,

Thank you for requesting a determination from our office about the above-referenced project. Based on our review of the materials you provided, we have determined that it does not require IRB review because it does not meet the definition(s) of research involving "human subjects" or the definition of "clinical investigation" as set forth in Emory policies and procedures and federal rules, if applicable. Specifically, in this project, you will be evaluating young adults perception of LoveLife's Youth Friendly Services initiative through conducting 45 minute interviews.

This determination could be affected by substantive changes in the study design, subject populations, or identifiability of data. If the project changes in any substantive way, please contact our office for clarification.

Thank you for consulting the IRB.

Sincerely,

Julia Duckworth
Research Protocol Analyst

This letter has been digitally signed

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