Protecting Adolescent Girls with HIV in Malawi

Protecting Adolescent Girls with HIV in Malawi:

Addressing Contraceptive Access and Vulnerabilities

By

Patience Bulage

Cambridge Scholars Publishing

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To my Parents: the Late Rev. Canon and Mrs. Mubbala, for being the torch bearers for my academic ambitions, imparting in me the value of education, the strong foundation laid for me – principles which have enabled me to get this far in life, for believing in me and pushing my life and career ambitions. Dad and mum, we did it!

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And lastly;

To the young girls and women of today and tomorrow, in Sub-Saharan Africa and world over, whether in or out of reach by conventional systems, and/but whose hands and voices raised are neither seen nor heard, and who are left out and left behind; the world knows about you!

TABLE OF CONTENTS

List of Tables and Figures xi

Foreword xii

Acknowledgements xiv

Description of the Book..... xvii

Ackronyms xix

CHAPTER 1: INTRODUCTION..... 1
1.1 Introduction to the study 1
1.2 Background to the study 6
1.2.1 Fertility control among adolescent girls (AGs) in developing countries 9
1.2.2 Situation analysis..... 11
1.2.3 Malawian context: The SRH situation of adolescent girls and young women (AGYW)..... 14
1.3 Rationale of the study 18
1.4 Research aim and objectives 20
1.4.1 Research questions 21
1.4.2 Specific objectives..... 21
1.5 Theory and Theoretical framework 21
1.5.1 Theoretical Framework 21
1.6 Study contribution to literature/knowledge..... 23
1.7 Scope of the study..... 24
1.8 Research/study process 25
1.9 Definitions of key terms used in the study..... 27

CHAPTER 2: SCOPING REVIEW; BARRIERS FACED BY ADOLESCENT GIRLS AND YOUNG WOMEN LIVING WITH HIV/AIDS IN THE UPTAKE OF CONTRACEPTION, IN SUB-SAHARAN AFRICA 28
2.1 Introduction..... 28
2.2 Rationale 28

2.3 Conceptual argument 30
2.4 Objective of the scoping review 30
2.5 Methodology for scoping review 31
2.5.1 Identifying the research question 31
2.5.2 Identifying relevant studies and search strategy 31
2.5.3 Study Screening and selection 32
2.6 Charting of data 34
2.7 Collating, summarizing, and reporting of results 34
2.8 Summary of Results 42
2.9 Data synthesis 42
2.10 Conclusion 44

CHAPTER 3: INTERSECTIONALITY OF SRHR, ADOLESCENCE, HIV, CONTRACEPTION AND POLICY 45
3.1 Introduction 45
3.2 Sexual and Reproductive Health and Rights, of adolescent girls living with HIV 45
3.3 Needs and aspirations of AGLHIV 48
3.4 Dual burden of HIV and teenage pregnancy and motherhood 51
3.5 Perceptions on family planning and use of contraception in SSA 54
3.6 Contraception use among adolescent girls and young women in Malawi 55
3.7 The importance of contraception for AGLHIV 56
3.8 Formulation and implementation of a policy 59
3.9 Health policy, its formulation, and implementation 62
3.10 The role of policy in promoting SRH for AGLHIV 64
3.11 Malawi and the ICPD 65
3.11.1 The ICPD and Sexual and Reproductive Health and Rights 65
3.11.2 Understanding the sequence of political, and socio-economic context for SRH in Malawi post-ICPD 1994 67
3.12 The SRHR policy framework and program environment in Malawi 71
3.13 Contraception, health and human rights for PLHIV 73
3.13.1 Guidelines for contraception for Women living with HIV 76
3.13.2 Rights-based family planning 77
3.14 Conclusion 79

CHAPTER 4: METHODOLOGY 80
4.1 Introduction 80
4.2 Study/Research design 81
4.3 Study population 82
4.4 Sampling procedure 84
4.5 Sample size 95
4.6 Data collection approaches and process 95
4.6.1 Phase one: Documents Review 95
4.6.2 Phase two: In-depth interview 101
4.7 Approaches to Data analysis 106
4.8 Ethical considerations 110
4.9 Challenges experienced 111
4.10 Study Limitations 112
4.11 Conclusion 113

CHAPTER 5: FINDINGS 114
5.1 Introduction 114
5.2 Structural and socio-cultural issues affecting the access and use of contraception BY AGLHIV in Malawi 114
5.2.1 Structural issues: 114
5.2.2 Socio-cultural issues 126
5.2.3 Synthesis on structural and socio-cultural issues 155
5.2.4 Conclusion 178
5.3 Policy provisions in place in Malawi to address the issues and risks faced by AGLHIV during the reach and use of contraception 178
5.3.1 Introduction 178
5.3.2 Synthesis on policy provisions available in Malawi to address the identified risks and vulnerabilities 199
5.3.3 Conclusion 206
5.4 Implementation challenges affecting the effectiveness of the available policy provisions 207
5.4.1 Introduction 207
5.4.2 Synthesis on implementation challenges affecting the effectiveness of the available policy provisions 235
5.4.3 Conclusion 238

CHAPTER 6: DISCUSSION AS PER HPT FRAMEWORK 240
6.1 Actors 240
6.2 Context 247
6.3 Process 248
6.4 Content 250

CHAPTER 7: CONCLUSION AND RECOMMENDATIONS 254
7.1 Conclusion 254
7.2 Recommendations (as per the Health Policy Triangle)..... 259

REFERENCES 265

ANNEXES
Annex 1: Data Collection Tools 282
Annex 1.1 Documents' Review Framework 282
Annex 1.2 PLHIV organizations' interview guide 285
Annex 1.3 Local service providers and implementing partners' interview guide 287
Annex 1.4 Policy makers' interview guide 289
Annex 1.5 Development partners' interview guide..... 291
Annex 2: Principal Investigator Request Letter to Targeted Participants 293
Annex 3: Informed consent forms (ICF) 295
Annex 3.1 : Malawi National Health Sciences Research Committee (NHSRC) Consent form (English version) 295
Annex 3.2: Malawi National Health Sciences Research Committee (NHSRC) Consent form (Chichewa version)..... 298
Annex 3.3 UKZN Humanities & Social Sciences Research Ethics Committee (HSSREC) ICF..... 301
Annex 4: Ethical Clearances/Approval Letters..... 303
Annex 4.1 Country ethical approval..... 303
Annex 4.2 Full Ethics Approval – University Ethics Committee 304

LIST OF TABLES AND FIGURES

Table 1 Types of studies included 33
Table 2 Data charting table..... 36
Table 3 Study population details 84
Table 4 Summarized sampling procedure 86
Table 5 Actual details of participating organizations, agencies and institutions..... 93
Table 6 Country policy and related documents reviewed..... 97
Table 7 Details of study participants interviewed..... 102
Table 8 Thematic analysis framework for the study..... 108
Table 9 Final analysis framework..... 109

Figure 1.1 Description of health systems interaction with environment for SRH..... 8
Figure 1.2 Map of Malawi..... 12
Figure 1.3 Walt and Gilson Policy triangle framework..... 23
Figure 1.4 Research process..... 26
Figure 2.1 Flow chart showing decision process..... 35
Figure 3.1 Stages Heuristic policy process..... 61

FOREWORD

The debate surrounding the control of sexuality of young girls – especially on early conception and child birth in many African societies has been going on for quite some time now. However, regardless of the actions taken at the international level and commitments made by countries towards ensuring the use of modern contraception, the attitudes towards it remain sub-optimal amongst some communities, and this makes the use of contraception difficult for young girls.

This book highlights the unique interplay of factors that an adolescent girl living with HIV in Malawi faces in the process of seeking and using modern contraception. The interplay of factors that include socio-cultural and structural issues contributes to and increases a young woman's vulnerability in society. Thus, it is tailored to a subpopulation of the adolescent population, which is disadvantaged and less researched, and this research is a dedication to identifying the unique needs of different adolescent groups and exploring the existing challenges specific to a particular subpopulation of adolescent girls who are living with HIV. It communicates the SRHR realities of adolescent girls living with HIV in Malawi, to decision makers and policy makers, highlighting the risks and barriers navigated in the process of access and uptake of contraception. In trying to find sustainable and effective solutions to teenage pregnancies, the research that was conducted fills the gaps of how policies are central to this phenomenon, and their importance to health systems development. The understanding of AGLHIV's realities ought to be reflected in policies and demonstrated through the implementation process as a way of providing social support and protection for the vulnerable, and as a practical way of creating a safe and enabling environment for AGLHIV to exercise their rights, and knowledge and abilities gained in the course of their development.

Therefore, this book is based on an assessment of the SRHR policy provisions in Malawi, with specific reference to the use of contraception by adolescent girls living with HIV, given the existing socio-cultural and structural challenges along the pathway to the use of sexual and reproductive health services. It highlights the importance of paying attention to the sensitivity and challenges attached to being HIV positive, and the

experience of pregnancy and motherhood at an early age, a double burden that young girls are suffering in Malawi.

The book focuses on an under-researched and disadvantaged subpopulation. It identifies their unique needs and explores the specific challenges they face. By addressing teenage pregnancies, this book highlights the crucial role of policies in health systems development. It argues that understanding the realities of AGLHIV should shape policies relating to this group, and their implementation.

The author clearly argues the need to diversify the package of proven approaches for adolescents by recognizing their varying vulnerabilities and emerging capacities, suggesting that paying attention to policies is one way to do that. It also serves as an advocacy tool for a diversified approach to adolescent care that acknowledges the varying vulnerabilities and capacities, and emphasizes the importance of policy attention. While previous studies have broadly addressed young people's barriers to service use, this book specifically focuses on this vulnerable subpopulation, their healthcare utilization pathways, and the role of policies.

Therefore, this book communicates the SRHR realities of AGLHIV to decision and policy makers, the risks and barriers navigated in the process of access and uptake of contraception, and serves as evidence for advocacy while holding responsible authorities accountable to earlier commitments made to, and on behalf of young people. It provides an evidence base for reference to recognize the policy gaps, implementation challenges, and ensure the design and preparation of adequate programs that promote contraceptive use and that can lead to improvement in health outcomes. Importantly, this book can be used as a guide for formulation and development of a policy document, or guideline dedicated to adolescent girls living with HIV that can be added to the existing general policies.

This book will specifically be a resource to researchers (Investigators, Academics, Scholars, Scientists, Students), and Health practitioners and programmers.

Dr. Collins Mitambo
Chairperson National Health Sciences Research Committee, Malawi

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DESCRIPTION OF THE BOOK

Adolescent girls face significant challenges in accessing and using contraception, including fear, denial of services, poor attitudes of health service providers, lack of confidence, and lack of privacy. These issues are even more severe for those living with HIV. Therefore, it is crucial to examine how current policies in Malawi address the vulnerabilities of this subpopulation. This book is an outcome of an independent research study that was conducted with the intent to provide answers to three specific objectives regarding contraceptive use among adolescent girls living with HIV in Malawi as follows:

i. To explore the socio-cultural and structural issues affecting the use of contraception among AGLHIV in Malawi
ii. To examine the policy provisions in place in Malawi to address the issues/risks faced by AGLHIV during reach and use of contraception
iii. To identify the implementation challenges affecting the effectiveness of the available policy provisions

This qualitative study, guided by the Health Policy Triangle framework, used primary and secondary data to examine the barriers to contraception for adolescent girls living with HIV in Malawi. Findings revealed that access and use are hindered by structural issues such as service provision modes, supply chain and infrastructure challenges, age restrictions, conditioned access, and service integration problems. Socio-cultural barriers include the high value placed on having children, male dominance, social stigma, non-disclosure of HIV status to partners, social sensitivity, perpetuation of harmful content, lack of social support, and poor risk perception.

Current policy provisions address gender-based violence, discrimination, stigma, community engagement, confidentiality, and emphasize adolescent girls and young women as a target population. However, these policies are often broadly stated, with gaps and discrepancies. Limitations include the reproductive age band, delayed policy revisions, lack of linkage between community health and biomedical departments, absence of safe spaces, limited understanding of policy concepts, inadequate risk mitigation measures, and poor dissemination of policies.

Effective policy implementation faces challenges such as cascading issues, insufficient funding, limited political will, low comprehension of policy directives, minimal target population participation, coordination difficulties, social resistance, effects of decentralization, low capacity of implementing partners, and slow behaviour change among targeted populations. Despite a seemingly favourable policy environment in Malawi, there are issues with harmonization and interest group representation, particularly for people living with HIV (PLHIV). This book recommends among other issues, that policymakers must prioritize HIV sensitive policies to support social protection programs for vulnerable populations, recognizing the benefits of a healthy, youthful population.

ACRONYMS

AA-HA!	Accelerated Action for the Health of Adolescents
ABYM	Adolescent Boys and Young Men
AGLHIV	Adolescent Girls Living with HIV
AGs	Adolescent Girls
AGYW	Adolescent Girls and Young Women
ALHIV	Adolescents Living with HIV
AMLHIV	Adolescent Mothers Living with HIV
ANC	Antenatal Care
ART	Anti-Retroviral Therapy
ASRH	Adolescent Sexual and Reproductive Health
AU	African Union
BLM	Banja La Mtsogolo
CBDAs	Community-based Distribution Agents
CBOs	Community-based Organizations
CCWPs	Community Child Protection and Case Management Workers
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
CHAM	Christian Health Association of Malawi
COMREC	College of Medicine Research and Ethical Committee
CPR	Contraceptive Prevalence Rate
CSE	Comprehensive Sexuality Education
CSOs	Civil Society Organizations
DHS	Demographic Health Survey
DPs	Development Partners
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe
EC	Effective Contraception
ESA	Eastern and Southern Africa
FP	Family Planning
FP2020	Family Planning 2020
FPAM	Family Planning Association of Malawi
GBV	Gender-based Violence
GDP	Gross Domestic Product
GoM	Government of Malawi
HAART	Highly Active Anti-Retroviral Therapy

HC	Hormonal Contraception
HDI	Human Development Index
HIV	Human Immuno-deficiency Virus
HPT	Health Policy Triangle
HSAs	Health Surveillance Assistants
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICPD	International Conference on Population and Development
IP	Implementing Partners
KPs	Key Populations
LMICs	Low and Middle-Income Countries
LSP	Local Service Provider
MDHS	Malawi Demographic Health Survey
MoEST	Ministry of Education, Sports and Technology
MoF	Ministry of Finance
MoGCDSW	Ministry of Gender, Children, Disability and Social Welfare
MoH	Ministry of Health
MoLG	Ministry of Local Government
MoLYSMD	Ministry of Labour, Youth, Sports and Manpower Development
MPoA	Maputo Plan of Action
MSM	Men who have Sex with Men
NAC	National AIDS Commission
NAF	National HIV and AIDS Action Plan
NSP	National Strategic Plan (for HIV and AIDS)
OVC	Orphans and Vulnerable Children
PHC	Primary Health Care
PI	Principal Investigator
PLHIV	People Living with HIV
PM	Policy Maker
PMTCT	Prevention of Mother-To-Child Transmission
PoA	Program of Action
RSSH	Resilient and Sustainable System for Health
SADC	Southern African Development Community
SBC	Social and Behaviour Change
SBCC	Social and Behaviour Change Communication
SCs	Simulated Clients
SDGs	Sustainable Development Goals

SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
SSA	Sub-Saharan Africa
STIs	Sexually Transmitted Infections
TB	Tuberculosis
UCRC	Universal Convention for the Rights of the Child
UHC	Universal Health Coverage
UKZN	University of KwaZulu-Natal
UN	United Nations
UNCPD	United Nations Commission on Population and Development
UNGA	United Nations General Assembly
USAID	United States Agency for International Development
VAWG	Violence Against Women and Girls
WHO	World Health Organization
WLHIV	Women Living with HIV
YFHS	Youth-Friendly Health Services
YKPs	Young and Key Populations
YPLHIV	Young People Living with HIV

CHAPTER 1

INTRODUCTION

1.1 Introduction to the study

In 2022, UNICEF estimated that there are 1.3 billion adolescents (aged 10-19 years) worldwide (UNICEF, 2022). This highlights the potential for enormous economic growth and social development in the countries with large youthful populations (UNFPA, 2014). As of 2022, the population aged 15 years and younger in Africa was recorded at 40% as compared to a global average of 25% (Saifaddin Galal, 2023). Some of the sub-Saharan Africa (SSA) countries are yet to begin the demographic transition, and without a decrease in the rate of population growth, these countries will find it difficult to create sustainable development. In addition, ensuring good health for the population is key, if SSA is to harness the demographic transition and dividends in the near future.

Adolescence is a normal part of human development, comprising of emerging sexual desires, behaviors and relationships (Hegde, Chandran, & Pattnaik, 2022). If supported by information and access to required health services and proper decision making, this process has the potential to result into a life-long positive impact in terms of sexual health and overall wellbeing and development of a person. However, due to a host of biological, socio and economic factors that come alongside this stage of life, adolescents in general can be at a higher risk of adverse sexual and reproductive health (SRH) outcomes mainly HIV and other sexually transmitted infections (STIs), unintended pregnancies and abortions, usually clandestine and unsafe. There is equally an elevated risk for those who give birth at that early stage of development/life, exposing themselves and their newborns to various possible risks of poor health outcomes, including death (Woog, Singh, Browne, & Philbi, 2015). Therefore, it is important to recognize that there are structural inequities and certain social environments that place certain groups of adolescents at increased risk and jeopardize healthy transitions to adulthood. Poor SRH outcomes can often be traced to adolescence, when most people become sexually active (WHO,

2011). This makes the SRH of the youth a fundamental issue to pay attention to.

For example; the sexual behaviour of HIV positive youths, whether infected perinatally, through risky behaviour or other ways, is not substantially different from that of HIV uninfected peers (Kancheva Landolt, Lakhonphon, & Ananworanich, 2011). Adolescents living with HIV (ALHIV) become sexually active and thus the need for targeted reproductive health services and policies to ensure uninterrupted access. Approximately a quarter of all HIV positive people, infected in various ways, are below 24 years of age (Landolt, Bunupuradah, & Chaithongwongwatthana, 2016). Half of this population is female. Whereas the needs of ALHIV may not be very different from those of HIV negative people, their increased susceptibility to certain medical conditions warrants that extra caution or attention be extended to put their SRH needs in consideration. In addition to their HIV regimen, effort is still required to guarantee easy access and use of other SRH services, while highlighting the rights of such vulnerable groups in SSA. Therefore, for the case of adolescent girls (AGs), and in the case of teenage pregnancy among adolescent girls living with HIV (AGLHIV) in SSA, effort is required to control the rampant teenage pregnancies. It is therefore imperative to assess how the current policy environment promotes or hinders the access and use of preventive services such as contraception, by means of offering protection to the vulnerable AGLHIV against the risks faced.

It is also important to recognize that while such policies may be intended to provide the desired good, they also come off either as positive or negative, especially in terms of meeting or hindering the fulfilment of the needs of AGLHIV. Previous evidence indicates that the constraints on access and use of SRH services mainly contraception exist not only in societal and cultural attitudes but law and policy too (Browne, Coffey, Cook, Meiklejohn, & Palermo, 2018; UNFPA, 2017) and other factors related to structural hinderances equally exacerbate these limitations. Thus, in addition to ensuring that related legal and policy provisions are in place, and that services are friendly, there is also need to uncover the vulnerabilities faced by AGLHIV in the process.

This book is therefore an outcome of an independent research study that was conducted with the intent to provide answers to the three objectives as follows:

i. To explore the socio-cultural and structural issues affecting the use of contraception among AGLHIV in Malawi
ii. To examine the policy provisions in place in Malawi to address the issues/risks faced by AGLHIV during reach and use of contraception
iii. To identify the implementation challenges affecting the effectiveness of the available policy provisions

Methodology

The methodology for this study was guided by the Health Policy Triangle (HPT) framework. Thus, the context, content, process and actors involved in the health policy of Malawi were given attention to during review of current policies and strategic documents, in regards to their linkage, contribution or influence on vulnerability as experienced in relation to the focus of this study, and in the interview questions.

The study was qualitative in nature, and relied exclusively on qualitative approaches of data collection, and analysis. It was both descriptive and analytic, allowing for literature and document review, also referred to as secondary data collection, and stakeholder mapping for interviews. Through thematic analysis, all the data that was collected was pooled together to form the final analysis for the study findings which are presented in chapter four of this thesis. This approach allowed the investigator to freely explore the phenomenon under study by providing flexibility in the review of the documents selected to the required depth to extort subject related information, and flexibility in posing questions from the in-depth interview guide which was used.

The choice and justification for qualitative research is that it allows for the in-depth exploration of topics, while providing valuable and rich insights generated through probing. It seeks to understand and explore, as well as providing opportunity to contextualize the phenomenon under study and permits interpretation of generated data into patterns (Sullivan & Sargeant, 2011), (Tiley, 2017). The qualitative techniques provide a unique depth of understanding due to the nature of open ended questions, allowing respondents to freely disclose their experiences, thoughts and feelings without constraint (M. Q. Patton, 2002). Given the focus of this study which is on policies and SRHR, the main points of discussion for this study included contextual issues such as culture, gender norms, policy processes in the country, implementation arrangements, which all required an in-depth and iterative process of engaging with documents and participants.

Qualitative methods offer a dynamic approach to research, where the researcher has an opportunity to follow up on answers given by respondents in real time, generating valuable conversation around a subject – something which isn't possible with a structured survey. Thus, the investigator can find answers for the 'why' that may arise during the guided discussion, because respondents have the opportunity to freely elaborate on their answers as was the case during this study. A qualitative method is equally concerned with the point of view of individuals involved in the study, which is later collated and interpreted to form actual thematic points to explain a given scenario (Sullivan & Sargeant, 2011).

The descriptive design was identified as suitable because the research was focused on casting light on the phenomenon at the time of study, by employing different data collection methods that could enable the description of the issues more comprehensively (Nassaji, 2015). Thus, it allowed for the generation of in-depth details from the study subjects to fill in the data gaps that were identified after the first phase of documents review. Additionally, it allowed for the generation of adequate information to answer the research questions by using different qualitative methods of data collection.

Ethical considerations

At country level, preliminary gate-keepers permission was sought from responsible representatives of targeted organizations to confirm their willingness to participate in the study. This was through direct contact by emails and physical follow up by the local team that supported the study. Additionally, the proposal for this study was reviewed and approved by the National Health Sciences Research Committee (NHSRC) at the Ministry of Health, Malawi (Annexure 4.1). At University level, ethical review and approval was sought from the University of KwaZulu-Natal Humanities & Social Sciences Research Ethics Committee (HSSREC). The full study ethical approval was provided by the HSSREC as indicated in Annexure 4.2.

During the data collection process, additional permission was sought from the relevant ministries to access the necessary national documents for review and the required interviews. For the interviews, copies of the informed consent form (ICF) were sent to respondents prior to the interview session to enable the respondent to read through and understand. During the interviews, oral consent was taken as well as permission to record each discussion. All respondents who participated in interviews consented to

both the participation and recording. All participation was voluntary and no coercion was involved. In preparation, the informed consent form was translated to Chichewa and both versions were available to suit participants' preferences. Organizations and participants were contacted prior to the interview scheduling, with all necessary explanations to request for their participation. Special attention was taken to ensure that representatives of PLHIV organizations were not adolescents, and were mainly persons in relevant leadership positions at the organization or specially seconded and suitable to participate in the study. There was no requirement for respondents to reveal their HIV status as it was not required by the study, and questions asked were strictly kept within the scope of the study. While the study was largely focused on adolescent girls (10-19 years) living with HIV/AIDS, they were not directly involved or approached as study respondents. All information required was generated from networks of PLHIV organization by sharing of program related information and interviews with identified officials who were not adolescents. The interviews were all virtual, online or telephone based in the preferred space of a specific respondent and using a platform of their choice. Special codes were allocated to each audio file recorded and maintained for the transcribed data report during data management to prevent identification. The copies of the informed consent forms used are attached in Annexure 3.1 – 3.3, and the ethical approval certificates are attached in Annexure 4.

Synopsis of the book

This book comprises of six chapters, that are systematically arranged as follows:

The first chapter sets the background for the study. Within this, detailed background information is provided to highlight the context in relation to the phenomenon under study and the country of study. The chapter also highlights the rationale of the study, the gaps in literature which the study sought to fill, the aim of the study, the research questions and objectives of the study, the theoretical framework upon which the study is hinged, the scope of the study, the research process followed, and provides a definition of key terms used. It also highlights the study's contribution to the body of knowledge, includes details of the rigorous process followed to gather the data that was analysed to produce the report, and ethical considerations followed. The second chapter presents the details of a scoping review which was nested into the study to provide more background on the phenomenon under study. The third chapter presents a comprehensive narrative detailing the intersectionality of topics relevant to the study focus. The fourth chapter

presents the findings for the study. These are presented in three different but connected sections, following after each other according to the order of the research objectives of this study – i.e.; research objective 1, research objective 2, and research objective 3. Each section is also covered with a discussion section. The fifth chapter presents, the main discussion based on the HPT framework. Lastly, the sixth chapter of this study presents the conclusion, and recommendations.

1.2 Background to the study

Teenage pregnancy is more common among poorer households (Woog et al., 2015). This trend may be attributed more to unmet need for contraception than to a desire to start having children earlier in life (UNFPA, 2018), and the challenges faced in accessing and seeking services. Girls from wealthier households have better information about sexual and reproductive health, and greater access to contraceptive services; they may even have access to safer, although illegal, abortion services (Vignoli & Cavenaghi, 2014). In some countries, minors, whether poor or rich, have limited access to emergency contraception and might need parental permission to access modern methods of contraception, such as the pill.

Family size is closely linked with reproductive rights, through the number of children a woman may be willing to have and when, which, in turn, are tied to many other rights, including the right to adequate health, education, and jobs. Where people can exercise their rights, there is a tendency to thrive. Where these rights are stifled, people often fail to achieve their full potential, impeding economic, social and individual progress, and this is common for girls and women in general (UNFPA, 2018). Yet, there is evidence that when a woman has the power and means to prevent or delay a pregnancy, she can have more control over her health and has increased possibility of realizing her full economic potential (Prata, Tavrow, & Upadhyay, 2017), (Onarheim, Iversen, & Bloom, 2016).

Since the 1994 International Conference on Population and Development (ICPD), reproductive health and rights have substantially improved around the world (UNFPA, 2018). People have more information about their reproductive rights and choices, and a greater capacity to claim their rights. However, in SSA today, there is no country that can claim that all of its citizens enjoy reproductive rights at all times. In many countries, most couples cannot have the number of children they want because they either lack the legal backing, economic and social support to achieve their preferred family size (Biseck;, Kumwenda;, Kalulu;, Chidziwisano;, &

Kalumbi;, 2015), or the means to control their fertility. With specific reference to women and girls, the unmet need for modern contraception prevents hundreds of millions from choosing smaller families and this can be attributed to a combination of factors including absence of supportive policies which can promote access to the needed services, as well as the general socio-economic and cultural environment.

In most countries in SSA, access to healthcare, notably SRH services is largely shaped by the health systems in place and guided by national and international legal and policy environments within which these systems operate coupled with the general social and economic contexts of peoples' access and use of desired healthcare services (Browne et al., 2018). Thus, there exists a dynamic relationship between the way services are provided, the contexts within which they are delivered, and how the target users access and use them (UNFPA, 2017), (Gruskin, Ferguson, & O'Malley, 2007) which warrants policies to support this routine occurrence which is demonstrated below.

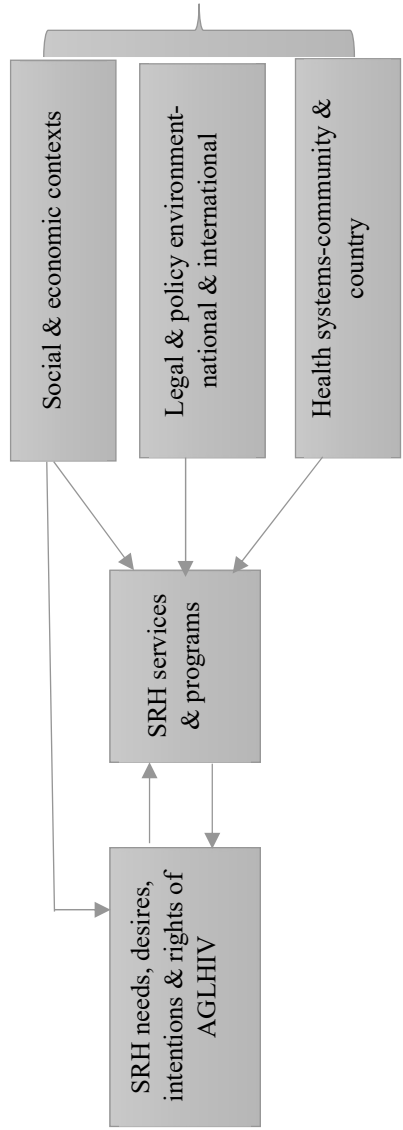

Figure 1.1 Description of health systems interaction with environment for SRH
Adapted from (Gruskin et al., 2007)