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The Quest for Maternal Survival in Rwanda

*Paradoxes in Policy and Practice from the
Perspective of Near-Miss Women, Recent Fathers
and Healthcare Providers*

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ACTA
UNIVERSITATIS
UPSALIENSIS
UPPSALA
2016

ISSN 1651-6206
ISBN 978-91-554-9747-7
urn:nbn:se:uu:diva-306604

Dissertation presented at Uppsala University to be publicly examined in Gustavianum, Akademigatan 3, Uppsala, Saturday, 17 December 2016 at 09:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in English. Faculty examiner: Professor Marie Berg (Institute of Health and Care Sciences, University of Gothenburg).

Abstract

Påfs, J. 2016. The Quest for Maternal Survival in Rwanda. Paradoxes in Policy and Practice from the Perspective of Near-Miss Women, Recent Fathers and Healthcare Providers. *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine* 1275. 91 pp. Uppsala: Acta Universitatis Upsaliensis. ISBN 978-91-554-9747-7.

Rwanda has made significant progress in decreasing the number of maternal deaths and increasing the number of antenatal care visits and childbirths at health facilities. This thesis seeks to illuminate potential barriers for Rwanda's goal for maternal survival. The studies explore the bottom-up perspective of policies and practices in regards to maternal care in Kigali. Semi-structured interviews were conducted between 2013 and 2016 with women who nearly died ('near-miss') during pregnancy, their partners, and with other recent fathers and community members, as well as healthcare providers who work within abortion care. The framework of naturalistic inquiry guided the study design and data collection. Analysis was conducted using framework analysis, thematic analysis and naturalistic inquiry.

The findings identify paradoxical outcomes in the implementation of maternal care policies. Despite recent amendments of the abortion law, safe abortion was identified as being non-accessible. Abortion-related symptoms continue to carry a criminalized and stigmatized label, which encourages risk-taking and clandestine solutions to unwanted pregnancies, and causes care-seeking delays for women with obstetric complications in early pregnancy. Healthcare providers had limited awareness of the current abortion law, and described tensions in exercising their profession due to fear of litigation. The first antenatal care visit appeared to require the accompaniment of a male partner, which underpinned women's reliance on men in their care-seeking. Men expressed interest in taking part in maternal care, but faced resistance for further engagement from healthcare providers. Giving birth at a health facility was identified as mandatory, yet care was experienced as suboptimal. Disrespect during counseling and care was identified, leading to repeated care-seeking and may underpin the uptake of traditional medicine.

An enhanced implementation of the current abortion law is recommended. Reconsideration of policy is recommended to ensure equitable and complete access to antenatal care: women should be able to seek care accompanied by their person of choice. These findings further recommend action for improved policy to better address men's preferred inclusion in maternal health matters. The findings of this thesis promote continued attention to implementing changes to strengthen quality, and trust, in public maternal care.

Keywords: abortion, maternal near miss, severe maternal morbidity, maternal health, male involvement, gender equity, empowerment, policy, bottom-up

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ISSN 1651-6206

ISBN 978-91-554-9747-7

urn:nbn:se:uu:diva-306604 (<http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-306604>)

*Till fammo
för allt*

Paradox ['perə,däks] NOUN

“A statement or proposition that, despite sound (or apparently sound) reasoning from acceptable premises, leads to a conclusion that seems self-contradictory”

Oxford English Dictionary

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Påfs J, Musafili A, Binder-Finnema P, Klingberg-Allvin M, Rulisa S, Essén B. (2016) Beyond the numbers of maternal near-miss in Rwanda – a qualitative study on women’s perspectives on access and experiences of care in early and late stage of pregnancy. *BMC Pregnancy and Childbirth*, 16:257.
- II Påfs J, Musafili A, Binder-Finnema P, Klingberg-Allvin M, Rulisa S, Essén B. (2015) ‘They would never receive you without a husband’: Paradoxical barriers to antenatal care scale-up in Rwanda. *Midwifery*, 31:1149-1156.
- III Påfs J, Rulisa S, Musafili A, Essén B, Binder-Finnema P. (2016) ‘You try to play a role in her pregnancy’ – a qualitative study on recent fathers’ perspectives about childbearing and encounter with the maternal health system in Kigali, Rwanda. *Global Health Action*, 9:31482.
- IV Påfs J, Rulisa S, Klingberg-Allvin M, Binder-Finnema P, Musafili A, Essén B. (2016) Healthcare providers’ paradoxical situation in providing abortion care and enforcing the amended abortion law in Rwanda – A qualitative study. *Manuscript*.

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Cover: Photograph of artwork on wall at Mibilizi Hospital, Rwanda.

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Abbreviations

ANC	Antenatal Care
FGD	Focus Group Discussion
GD	Group Discussion
HCP	Healthcare Provider
IDI	Individual In-depth Interviews
MDG	Millennium Development Goal
MNM	Maternal Near-Miss
PMTCT	Prevention of Mother-to-Child Transmission of HIV
WHO	World Health Organization

Introduction

Improved maternal survival has been a global target for decades. Since 1990, maternal deaths have decreased by nearly half – but with stark disparities between countries. In sub-Saharan Africa, a woman’s lifetime risk of dying as a result of pregnancy or childbirth is estimated to be more than 100 times higher than for a woman in a high-income country (1). Rwanda stands out among sub-Saharan nations in reducing maternal deaths and was one of the few countries to achieve the Millennium Development Goal 5a by decreasing maternal deaths by 75% between 1990 and 2015 (2). As well as decreased maternal deaths, up to 91% of all childbirths are now reported to take place at health facilities (3), nearly all women go for one antenatal care visit, and 87% attend their first antenatal care visit with their partner for HIV testing (3,4). Rwanda has also significantly decreased out-of-pocket expenditure for health by introducing its community-based health insurance program (5). These advancements reflect rapid improvements and Rwanda is often cited as a success story. Yet, few studies have looked beyond the numbers to explore how the users of these services actually perceive and experience them.

This thesis seeks to contribute to Rwanda’s goal for maternal survival by presenting the perspectives of women who nearly died (‘near-miss’) during pregnancy, as well as those of their partners and other recent fathers, community members, and healthcare providers who work within abortion-related care. This will bring forth the bottom-up perspective of policy and practice in relation to maternal care.

The Global Quest for Maternal Survival

Global priorities and goals to reduce maternal deaths

The issue of maternal death was brought to international attention in 1985 when the World Health Organization (WHO) launched a first global estimate revealing that half a million women died every year due to pregnancy, and Rosenfield and Maine (1985) raised the question: “*Where is the M in Maternal and Child Health?*” (6). The Safe Motherhood Initiative, launched in 1987, was one of the first major efforts to reduce maternal deaths. Despite the advocacy of several plans and interventions, the goal to reduce maternal deaths by 50% by the year 2000 was not met (7). Parallel to the Safe Motherhood initiative, the International Conference on Population Development in Cairo in 1994 put sexual and reproductive health and its importance for maternal health on the agenda (8). The Fourth World Conference on Women in Beijing in 1995 built on this notion by recognizing sexual and reproductive health as a human right.

The goal for reducing maternal deaths was raised again when 8 global Millennium Development Goals (MDG) were stipulated in the year 2000. These goals were set to improve health and wealth, and promote gender equality globally. The fifth goal aimed to reduce maternal deaths by at least 75% between 1990 and 2015 (5a) and to achieve universal access to reproductive health (5b) (9). Maternal deaths dropped by nearly 44% globally, but only nine countries reached the goal (5a) (1). To follow up on the MDGs, 17 Sustainable Development Goals (SGD) were defined in 2015. The specific targets for maternal survival are to decrease the global maternal mortality ratio to less than 70 maternal deaths per 100 000 live births by 2030, with no single country having a maternal mortality ratio greater than 140 maternal deaths per 100 000 live births (10). Focus is also set on ensuring universal access to sexual and reproductive health and rights, and on eliminating all forms of violence and harmful practices against women and girls, as well as discriminatory laws, policies and practices (10).

Parallel to these global goals, the World Health Organization (WHO) recently launched a Global Strategy for Women’s, Children’s, and Adolescents’ Health to end preventable deaths and ensure that all women, children and adolescents, can attain the highest achievable standards of health and well-being (11). The World Health Organization (WHO) has also released a plan for Ending all Preventable Maternal Mortalities (EPMM). This is based on a holistic and rights-based approach, with focus on inequities in access, quality, and outcome of care, and the provision of information and adequate options for all girls and women to exercise their own reproductive choices (12).

Causes of maternal deaths

Causes of maternal deaths are manifold, but most complications leading to maternal deaths can be prevented or treated (12). Causes can be direct, resulting from hemorrhage, infection/sepsis, hypertensive disorder, obstructed labor or unsafe abortion; or indirect, resulting from previously existing disease or a disease developed during pregnancy (13). Indirect causes may also be rooted in economical, geographical and social matters, causing delayed access to care (14); or in structural health-system challenges, such as the shortage of drugs, equipment and necessary supplies; or the absence of updated guidelines and information on evidence-based care, and the shortage of skilled healthcare providers (15,16). Recent recommendations highlight the need for a scale-up of equitable and respectful evidence-based quality of maternal care, globally (17).

The exact number of abortion-related deaths remains unknown, but is estimated to be 7–9% of all maternal deaths globally, and around 9% of all maternal deaths in sub-Saharan Africa (13). Unsafe abortions are defined as terminations of pregnancies carried out under dangerous or unhygienic conditions, or under incorrect usage of medication, either self-induced or managed by a person lacking qualifications (18). Unsafe abortions are preventable, but occur in part due to restricted access to safe abortion services and contraception (19). Legal avenues with access to safe abortion are found to be vital (19,20), yet aspects of affordability, awareness and stigma are also important to facilitate access to the necessary services (21,22).

The maternal near-miss concept

Maternal near-miss, also referred to as “severe maternal morbidity” or “life-threatening morbidity”, is defined as “a woman who nearly died but survived a complication that occurred during pregnancy, childbirth, or within 42 days of termination of pregnancy” (23). Varying standards have been used to identify near-miss cases. In order to facilitate the comparison between different studies, the WHO suggested a set of identification criteria in 2009 including certain clinical criteria, laboratory-based criteria, and management-based criteria (23). However, to categorize a near-miss in a resource-poor setting, it is recommended that the criteria are modified based on the equipment available to identify and treat cases, which makes certain conditions potentially more life-threatening (24).

Near-miss has been a valuable approach, mostly in quantitative, but also in qualitative, studies (25,26). During recent years, this approach has been used extensively in studies in the sub-Saharan setting, including: Burkina Faso,

Tanzania, Uganda, and Zambia (27–32). Near-miss can be used to monitor the quality of maternal care and function as a proxy for maternal mortality, as these women often share similar trajectories with women who do die, but can give their own perspective of what actually happened (33,34). It is suggested that a distinction is made between near-miss events upon arrival and after arrival to the facility, as the former can be used specifically to identify pre-facility barriers (35,36). Although near-miss cases can be portrayed as success stories because the women survived, these cases are also a reminder about the importance of the quality, and continuum, of maternal care (37). Follow-up studies of women with near-miss events have identified both a risk of mortality after the near-miss (37) as well as social and economical consequences, affecting not only the woman but the whole family (27,31). Limitations to the near-miss approach include that it fails to capture women who never reach the facility, that it cannot be used by asking women to self-report but are dependent on diagnostics, and that the criteria chosen may fail to identify cases (23,38).

Relatively few studies have included near-miss events that occurred in early pregnancy, and fewer have used a qualitative approach to study such cases (32,39–43). At the initiation of this research project, near-miss had still not been reported to be used to assess maternal care in Rwanda. Since 2015, three studies have been published, presenting quantitative data from hospitals in Rwanda (40,44,45). These also included women with near-miss in early pregnancy.

Rwanda's Quest for Maternal Survival

Rwanda is a landlocked, low-income country in sub-Saharan Africa, with a dark history of the genocide that occurred from April to June in 1994, killing more than one million people. Twenty years later, the same country reports low levels of crime, and has a government with high development ambitions and a zero-tolerance policy for corruption. The development of Rwanda has been praised for its achievements, but also criticized for its tight censorship and controlling, top-down style of governance and policy implementation in achieving its goals (46–48).

Demography

Rwanda has undergone several demographic changes since the genocide. In pre-genocide Rwanda, Catholicism was the dominant religion. Since then, the religious landscape has changed, with an increasing number of people adopting the Pentecostal faith (49). Christianity is still the dominant religion, practiced by 93% of the population, with a distribution of 44% being

Catholic, 38% Protestant, and 12% Adventist. Those of Muslim faith remain a minority of 2%, and only 0.4% of the population report to have no religion (3). The official languages are English, French and Kinyarwanda, with most of the rural population speaking only Kinyarwanda. Poverty is present, and it is estimated that 39% are living under the poverty line (defined as being unable to buy a basic basket of food) (3). The majority of the population is still dependent on agriculture, yet this is reportedly much lower in Kigali than in the rest of the country (3).

Following the genocide, thousands of women were widowed and children orphaned (50). Today, Rwanda has a young population with half of its 10.5 million inhabitants being under the age of 20. Therefore, a key priority is to reduce population growth, as the current population density is the highest in sub-Saharan Africa (408 per square km) (3). With a high fertility rate and high number of unintended pregnancies, improving reproductive health has become a top priority (51).

Rwanda is organized into five provinces, including Kigali city as one. These are organized into districts, which are further divided into sectors, cells and, finally, villages (3). A village is the smallest administrative unit, and goes under the name ‘umudugudu’, which can be translated to mean a ‘village’, or in Kigali, to a ‘neighborhood’. Each ‘neighborhood’ has a committee of five people, with one being the local chief. These individuals represent the lowest level of the hierarchical governance pyramid, and are in daily contact with people living in their area (3).

The national agenda for improved health and wealth

In the early 2000s, Rwanda launched Vision 2020, a development plan with social and economic targets. Its main goals are to construct a united Rwandan identity, improve gender equality, raise people out of poverty, and become a middle-income country by the year 2020 (51). In order to achieve these goals, priorities are set on increasing education, health and wealth among the citizens. The Vision 2020 plan has fed into the overarching Health Sector Strategic Plans and specific policies (52–54). The overall objective of the health sector is to ensure universal accessibility of equitable and affordable quality health services for all Rwandans (53).

Rwanda has developed strategies to communicate the goals of Vision 2020 and its policies to the population. On a community level, ‘Umuganda’, or the gathering of the people of each neighborhood for community work once a month, is also an occasion where issues and plans are discussed (55,56). It is noted that citizens of Rwanda are usually well aware of national policies (57,58). Although this awareness may not always lead to action, it has been

observed that guidelines and regulations tend to be followed, sometimes driven by the fear or threat of severe consequences if not obeyed (55).

Strengthening of the Rwandan health system

Rwanda has made significant progress in rebuilding its health system since 1994. The health system is decentralized and has a pyramidal structure, with the community health worker at the bottom, followed by the health centers for primary treatment and care, and district hospitals and referral hospitals at the top (52). Patients are, when needed, referred from the lower to the higher level of the health facilities and are expected to follow these regulations except in the case of emergencies. The Ministry of Health provides resources but allows some independence on service implementation. Parallel to the public health facilities, there are a number of faith-based health facilities, which also receive assistance from the government. In the urban areas, there is also an increasing number of private clinics (59). Alongside these, there is an informal 'traditional healthcare sector' providing alternative 'traditional medicine'. An increased adherence to such alternative solutions by many Rwandans was anecdotally reported in the document outlining Health Sector Policy in 2015 (53). Traditional practitioners are currently allowed to provide certain services if they are registered, but only a few are (5). To control traditional medicine and mitigate malpractice, a regulatory framework and code of conduct is planned to be developed (53).

To strengthen the health system, a key priority has been to increase human resources. The shortage of educated health staff is a main challenge in Rwanda. The indicators for the number of doctors per inhabitant is 1/15 428; and for nurses is 1/1200 (60). Therefore, the task-shifting of training community health workers (CHW) to deliver primary health services and health education at the grassroots level was implemented. Three persons in each village or neighborhood are trained, with one, preferably a woman, being assigned to focus on reproductive and maternal health matters. The role of CHWs has reportedly contributed to pregnant women's increased uptake of health facilities for antenatal counseling and childbirth (61,62). Since 2012, a 7-year-long partnership with specialists from the United States has been ongoing. These specialists in health management, nursing, medicine and oral health are training and supervising both students and staff. When this program finishes in 2018, Rwanda is planning to be able to continue with its own teachers and clinicians (63). Another key strategy is also the payment-for-performance (P4P) of healthcare providers. This was introduced in 2005 to increase motivation among health workers and ensure the quality of care. Studies suggest that it has improved patients' satisfaction, as well as the quality of certain maternal health services (64,65). Yet, no link has been found between this strategy and increased antenatal care, and the

poor uptake of the four antenatal care visits available to women persists, which is argued to potentially be due to the poor financial incentive offered to providers (64).

Priorities for maternal survival in Rwanda

To improve maternal health and related care services, Rwanda is highlighting the need for *equity* by providing equal and universal access to the required healthcare; and is highlighting *continuum of care* by preventing unintended pregnancy, and by providing the highest attainable standard of care during pregnancy and childbirth and in the post-natal period (54). *Maternal care* in Rwanda covers the spectrum from (post-)abortion and antenatal care to care during childbirth and the post-partum period.

Rwanda has managed to improve certain indicators regarding maternal health substantially (see Table 1). In the following section, three main priority areas are elaborated: *Decrease of abortion-related deaths*; *Institutionalization of maternal care*; and *Increase of men's involvement in maternal health*.

Table 1. Key characteristics on maternal health in Rwanda. Adapted from the Rwanda Demographic and Health Survey 2005, 2010 and 2015. Maternal mortality ratio is the number of maternal deaths per 100 000 live births.

	2005	2010	2015
Maternal mortality ratio	750	487	210
<i>Place of delivery</i>	%	%	%
Health facility	28	69	91
Home	70	29	8
<i>Antenatal care</i>	%	%	%
One visit	94	98	99
Four or more visits	13	35	44
Total fertility rate	6	5	4

Decrease of abortion-related deaths

Complications arising from unsafe abortions and miscarriage are defined as a significant public health challenge in Rwanda (66). A recent estimate indicates that 7% of maternal deaths were attributed to abortions in 2013, but the number is thought to be higher in reality (67). A recent hospital-based study on near-miss during pregnancy in Kigali disclosed that 45% of all severe morbidities and 28% of mortalities were abortion-related (40). It is estimated that nearly every second pregnancy is unintended, and around 22% of these result in induced abortions (68,69). Among women with post-

abortion complications requiring treatment, only two-thirds are estimated to seek post-abortion care (68).

Of the abortions that do take place, it is assessed that 17% of them are self-induced, or induced with the help of a friend, and 34% are performed by a traditional healer (70). The rest, 49%, are estimated to be carried out by healthcare providers, who seldom have the right training in how to perform safe abortions (70). Research knowledge in relation to abortions in this setting is scarce and a qualitative perspective was explicitly stated as being needed by Basinga et al. in 2012 (68).

Increase in uptake of contraception – Decrease in unintended pregnancies

In line with Vision 2020, particular focus has been placed on decreasing the unmet need of family planning. A goal has been set to reduce the fertility rate to 3 children in 2020 (51). The current fertility rate is 4.3 in rural areas, and 3.6 in urban (3). To reach the goal, as well as to prevent unwanted and high-risk pregnancies to minimize unsafe abortions, the usage of modern contraceptives is encouraged. These contraceptives are also provided for free, or the cost is subsidized (71). Women pay for the materials used for injections, such as needles, themselves. The uptake is slowly increasing. In 2005, 15% of sexually active women reported the use of modern contraceptives (72), and in 2015 the number had increased to 28% (3). Among married women, the usage of modern contraceptive is estimated to be 48% (3). Reluctance to increase the uptake of these contraceptives seems to particularly be due to the fear of side effects, misconceptions regarding fertility and pressure from partners (57,73).

Amendments to the law: Exemptions from criminal liability for abortion

Despite strong opposition from religious leaders and organizations, the previously strict abortion law was revised in 2012 to allow induced abortion for pregnancies resulting from rape, incest or forced marriage, or if the “continuation of pregnancy seriously jeopardizes the health of the unborn baby or that of the pregnant woman” (74). This amendment also included a reduction in the prison sentence; from 10–15 years to 1–3 years for women who undergo an illegally induced abortion, and to 2–5 years for a person who induces an abortion after mutual consent, and, 10–15 years for a person who induces an abortion without her consent. If this person is a medical doctor, a midwife, or a pharmacist, he/she can also be suspended from practicing the profession for a period of 3–5 years (74).

To be allowed a legal abortion, approval is needed from the court along with consent from two medical doctors. For cases where the health of the woman is jeopardized, consent from two medical doctors should be enough. However, given this approval procedure, and the persisting cultural and

religious stigma associated with abortion in this setting, abortions are reported as difficult, or impossible, to obtain (74,75).

Expanding access to post-abortion care

There is an identified need to improve the quality of post-abortion care. Despite this service being available at health centers, most women presenting with complications were transferred to referral or district hospital for further management (70). Some complications are prevalent solely due to unhygienic or unskilled management (76,77). Therefore, the Ministry of Health put forth a National Comprehensive Treatment Protocol for Post-abortion Care Services, in 2012. This protocol focuses on increasing access to post-abortion care services. The focal point was to introduce misoprostol tablets for treatment of incomplete abortions at *all* levels of the healthcare system by healthcare providers, not only physicians, and to promote manual vacuum aspiration for emergency treatment in health centres and hospitals. Another core component is to provide contraceptive counselling to the woman prior to her being discharged, and that no additional visit is needed if no complications arise (78). These clinical recommendations and task-shifting are in line with current recommendations from the WHO (79,80). Other studies from sub-Saharan Africa show that task-shifting contributes to accessible and cost-effective care, and that misoprostol is a highly acceptable treatment for incomplete abortions (81–84).

To date, healthcare providers' perspectives on induced abortions and abortion care in Rwanda has scarcely been studied (77). Research from other sub-Saharan settings suggests that healthcare providers have an important influence on abortion services, and that they are balancing legal restrictions, social norms and their own moral convictions in their work (85–89).

Institutionalization of maternal care

Increase facility-based childbirths

The maternal mortality ratio has decreased notably since 2005 (Figure 1) and the current ratio of 210 deaths per 100 000 live births in Rwanda is lower than the estimated 546 in sub-Saharan Africa as a whole (1). Rwanda adopted the policy of increasing facility-based childbirths by skilled personnel as part of the strategy to achieve the MDG5 by 2015 (90).

Skilled personnel are defined as healthcare providers who are trained in managing childbirth and the immediate postnatal period, and who can identify, manage and make a referral if complications arise (91). In Rwanda, a woman is usually assisted by a nurse (67%) or doctor (19%) during childbirth (3). Trained midwives are few, and they assist only around 3% of childbirths (3). Healthcare providers, particularly nurses, may lack proper

training (45,67), and health centers, where the majority of childbirths take place, often lack the necessary training and equipment to handle emergency cases, with delayed treatment and referrals being the contributing reasons for the persistently high number of deaths (67).

The current high uptake of facility-based childbirths is argued to be a result of the community-based health insurance program, an increase in health education provision, and policy changes (61). Yet, it has also been described to be a result of the fines imposed on women who do not deliver at a facility, and the outlawing of traditional birth attendants (92,93). The traditional birth attendants were considered to pose an increased risk of maternal mortality as they are untrained in managing complications (61). Therefore, the government has attempted to integrate them into the system of CHWs instead, to encourage women to deliver at a facility (93). However, despite the high uptake of facility-based childbirths, a recent study from the perspective of healthcare providers and traditional healers argues that women's reliance on traditional medicine is persisting, and is estimated as being prevalent during pregnancy (94).

To facilitate the work of CHWs in assisting pregnant women in their neighborhood, a RapidSMS intervention was put in place. Each pregnant woman is registered, and the CHW receives a reminder of when to check on the woman. Similarly, a CHW can send a message to the closest health center, to prepare them if a woman in labor is on her way (95).

Antenatal care and partner involvement

Antenatal care in Rwanda is regarded as important to reduce risks and complications, and the country has adopted the WHO recommendation of four visits, initiated in early pregnancy, and provided free of charge at a public health center (3). These visits should include the precautionary management of anemia and preeclampsia, tetanus toxoid vaccination, and provision of health information related to danger signs during pregnancy (96). Antenatal care is provided by a healthcare provider, who is most commonly a nurse (3).

Rwanda is encouraging male partner involvement at the first antenatal care visit. The campaign, referred to as "Going for the Gold", was launched to encourage male participation specifically for HIV testing and to prevent mother-to-child transmission (PMTCT) (97). The HIV prevalence is 3.6% for women and 2.2% for men (3). Rwanda records a high number of attending partners compared to its neighboring countries, at 87% (4). Yet, how male involvement may affect women's participation in antenatal care has not been studied.

Although the uptake of antenatal care is high, and incentives are put in place offering free delivery if a woman attends all four visits (98), few manage to initiate their visit in a timely manner. According to the Demographic and Health Survey from 2015, 56% of women made their first visit within the fourth month of pregnancy (3). In 2010, the number was only 38% (69). Late initiation of antenatal care is suggested to partly be grounded in cultural reasoning of wanting to protect the pregnancy from bad fortune, and therefore also hide a pregnancy from the community (99). Other reasons for timely initiation are, from the healthcare providers' perspective, suggested to be ignorance, no insurance, long travel distance and no partner support (98). A study based on the Demographic and Health Survey suggests that high parity, or facing an unintended pregnancy, are also reasons for delayed attendance (100). Comparably, being covered by the community-based insurance scheme or other insurance, seeking care at a private facility or being married were found as explanations for timely uptake (100). However, qualitative data regarding women's and men's perspectives on these matters are lacking.

Community-based health insurance – 'Mutuelles de Santé'

To improve financial accessibility, a community-based health insurance program was introduced in 1999. This community-based health insurance, also called 'Mutuelles de Santé' has contributed substantially to an increased uptake of health services, particularly among lower socioeconomic groups (101). Members pay only 10% of the costs of care and selected medicines (61,102). Currently, 73% of the population is enrolled, which is a decrease from 91% in 2010 (60,102). The decline may be due to the increased cost of the insurance scheme. The system of payment was revised in 2011 and now depends on the enrollee's socioeconomic classification. To address poverty and reduce social inequality, Rwanda has a system of grouping people according to their socioeconomic status, taking into account not only income, but also assets. With health insurance as an example, a person will either get the insurance for free, or pay a lower price, depending on the socioeconomic group that one is categorized within (99). Civil servants and those in the military, along with their respective family members, are covered by their own insurance scheme (103).

Increase of men's involvement in maternal health

On the global agenda, men's participation in reproductive and maternal health was already considered a cornerstone in the overarching agenda for gender equality at the International Conference on Population and Development in Cairo in 1994 (104). In Rwanda, within Vision 2020 and the crosscutting agenda for gender equality, the traditional gender norms are acknowledged to play a role, and thus these norms are stressed as important aspects to address in improving maternal health (52,105). So far, the specific

action point listed in relation to maternal health is to include men in the program for PMTCT, with the primary aim of assessing their HIV status (52). Compared to other countries in sub-Saharan Africa, attendance of men in antenatal care is found to be high in Rwanda (4).

Internationally, the inclusion of men in antenatal care has been a main initiative, primarily for counseling and testing to ensure PMTCT, as well as to improve men's awareness of the symptoms of pregnancy-related complications (97). In the sub-Saharan setting, involving men during pregnancy is found to increase their understanding of potential risks and the necessity to seek timely care, and thus contribute to women's uptake of maternal care (106–108). Barriers to increased male involvement are argued to be rooted in them not feeling welcome or being denied access to the labor ward, experiencing maternal care as a female domain, or due to negative attitudes from healthcare providers, suboptimal care, and long queuing times and conflicts with working obligations (109–112).

A promotion program is currently taking place in Rwanda, called MenCare, to engage men in caring activities, such as caring for children and participating in household tasks, and similarly, to inform them about reproductive and maternal health matters (113).

The quest for gender equality/equity in Rwanda

Gender equality¹ has attained a main priority on Rwanda's political agenda. The progressive work is often portrayed as a unique example in Eastern Africa. Prior to 1994, Rwandan society was largely patriarchal and men enjoyed most of the privileges. Women were expected to obey men, had limited autonomy and could neither own nor inherit land (114). An important turning point came in 2003, when the government established policy priorities to increase women's roles, and again in 2009, when the government adopted the national gender policy (115). This policy has a clear aim of integrating a gender focus into all development sectors (105). Vision 2020 also explicitly states that in order to strengthen gender equality, the country will “*practice a positive discrimination policy in favor of women*” and the focus is set on empowering women (51).

One major step taken was the introduction of gender quotas for increased representatives of women at all decision-making levels. This aspect has led to Rwanda becoming the first country in the world with a female majority in their parliament (116). Another important advancement was the revision of

¹ Equality and equity are used interchangeably in policy documents, but in relation to maternal health, gender *equity* is most commonly used (52).

laws and policies to decrease harm for vulnerable women. Women now have the same right to inherit as men, and marital rape and beating your wife are today stated as punishable acts (117,118). Girls have also surpassed boys in school enrollment at primary and secondary level, but their numbers are still lagging behind in tertiary education (3).

Despite these major structural changes, studies are reporting various effects on the ground. Whereas some studies are claiming that traditional norms and roles of women and men are slowly changing, and that women's lives have changed in a positive direction (114,119), others argue that men in particular pose resistance to the promotion of gender equality (50,120). Nevertheless, there are indications that men with higher education and incomes are expressing more gender equitable ideas (119,121). However, recent studies also report that men perceive that women will start misusing the power that they may attain from these new policies (115). Men's violence against women remains a challenge, and is argued to have increased during the last few years, both in regards to physical and psychological violence, with sexual violence being particularly prevalent (115,118,122). National efforts have been put in place to provide services for victims of gender-based violence (123), yet, many cases go unreported, often because of fear of repercussions (50,118). Gender-based violence is also found to be socially accepted, and to a higher extent among women, than men (3).

Gendered expectations appear to be deeply rooted in Rwandan society. Men are expected to be the breadwinner and have dominance in decision-making, and the women are expected to take care of the household and children (113,124). Individuals who challenge these norms have been reported to face adverse consequences in their intimate or community relationships, and are accused of having 'rejected the traditions' (50,113,115).

Aim

The overall aim of this thesis is to gain a deeper understanding of the bottom-up perspective on policy and practice in relation to maternal care in Rwanda.

The aims of the separate papers are:

- To explore care-seeking and experiences of maternal care among women who suffered a near-miss event in the early or late stage of pregnancy (*Paper I*)
- To explore perspectives and experiences of antenatal care among women who suffered a near-miss event, their partners, and community members (*Paper II*)
- To identify recent fathers' perspectives about male partner involvement during childbearing and maternal care-seeking (*Paper III*)
- To explore Rwandan healthcare providers' perspectives on the realization of the amended law, their attitudes toward induced abortions, and their experiences of working within abortion and post-abortion care (*Paper IV*)

Methods and Research Process

This thesis is guided by the framework of naturalistic inquiry as presented by Lincoln and Guba (1985) (125). Data were collected in Kigali, Rwanda during the 9-month period between March 2013 and April 2014, and a final month-long visit in March 2016. Table 2 provides an overview of the data collected and the methods of analysis used for each paper.

Table 2. Overview of the data collected and the methods of analysis used for each paper.

	Participants	Data collection	Analysis
I	47 ‘near-miss’ women	Individual interviews	Naturalistic inquiry
II	47 ‘near-miss’ women, 13 partners, 34 female and 26 male community members	Individual interviews Focus group discussions	Framework analysis
III	32 recent fathers (13 partners to ‘near-miss’ women)	Individual interviews Group discussion Focus group discussions	Naturalistic inquiry
IV	52 Healthcare providers	Individual interviews Focus group discussions	Thematic analysis

Description of Methods

Naturalistic inquiry as methodological base

There are basic assumptions within the framework of naturalistic inquiry that have guided this work (125,126). Naturalistic inquiry sees *realities* as constructed and multiple. These realities can only be explored *holistically*. The primary principle of the naturalistic inquiry framework is that inquiry cannot be separated from context, and the research should therefore be conducted in the *natural* setting of the participant. Naturalistic inquiry argues that *objectivity is unattainable*. Research is seen as interactive and a process where both the researcher and participant have influence on each other – making research a state of *mutual simultaneous shaping* of the

inquiry. As for all qualitative studies, *generalization* is not possible; instead, the aim of naturalistic inquiry is to describe a specific case, and this description will be highly contextualized. Inquiries are also seen as having a *value bond* – that is to say, the researcher’s values, as well as the values residing in the context, will influence the choice of focus and specific research questions within the area of investigation.

The method of naturalistic inquiry was chosen as it allows for an explorative approach, and to capture the ‘bottom-up’ voice in the setting. Naturalistic inquiry has been previously utilized for these purposes in maternal health research (127,128).

A study using naturalistic inquiry is not fully designed beforehand, but it does have a typical *flow* or development, typically referred to as emerging design (129). This process, utilized in this project, is detailed in a simplistic flow-chart below (Figure 1). As a researcher, one has oneself as the research instrument, as well as one’s tacit knowledge. Lincoln and Guba (1985) argue for entering the field as a *learner* in order to build an understanding of the inquiry within its *natural* context, instead of building a hypothesis from previously applied theories (125).

Within the heart of naturalistic inquiry lies the ‘hermeneutic-dialectic’ process, which means that throughout the research process, the researcher is uncovering and interpreting the meaning (i.e. hermeneutic) of what is happening in the situation, and then comparing and confronting this meaning purposefully throughout the encountered situations (i.e. dialectic) in order to achieve a consensus between them all (126). Throughout this process, the researcher will carry out successive repetitions of four elements: purposive sampling, preliminary analysis, redefinition of and redesign the study if needed; and repeat. Conducting participant observations is part of this process, and is accomplished by observing, participating, reading documents and constantly testing one’s assumptions. Naturalistic inquiry allows for a constant redefinition of the interview questions in order to gain a deeper grasp of the complex phenomena occurring within the area of study determined by the research question. When researchers perceive that no new information has been contributed by participants about a specific phenomenon, that is to say, when *saturation of categories* (referred to as ‘topical saturation’ in this thesis) (125) occurs, it is suggested that the researcher repeat the process for a second round (Figure 1). This process allows at least some of the earlier respondents and some community members an opportunity to react to the constructions of others, that is to say, *member checking* to take place. When this has been completed, the final analysis is conducted on these joint constructions with the goal of writing a case report containing a thick description of the phenomena.

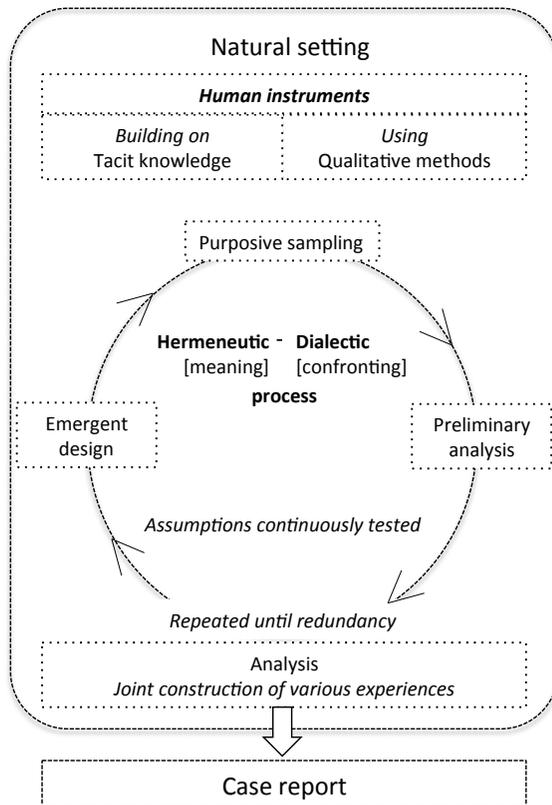


Figure 1. The ‘flow’ of data collection guided by Naturalistic Inquiry. Picture adapted by Páfis from Lincoln & Guba (1985) p.188

In summary, the framework of naturalistic inquiry takes a subjectivist epistemological standpoint by seeing the findings as being created in an interaction between the researcher and participants; as well as from a relativist ontological standpoint, by understanding that realities exist as multiple constructions, in people’s minds (130). Guba (1990) argues that naturalistic inquiry differs from what is referred to as ‘conventional’ methods, particularly positivist and post-positivist methods, and positions itself within a more humble approach to generalization and ‘truth’ (130).

Research setting

This study was conducted in Kigali, the capital of Rwanda. With its 1.2 million residents, Kigali is the only major city in Rwanda (3). The city is clean and orderly, with the construction of new high-rise buildings constantly ongoing. Kigali is a city of contrasting neighborhoods of wealth and poverty. Kigali is a safe and secure city to live in compared to other cities in the region. The institutions in charge of the city (the Police and

Army) are vigilant day and night to protect the security of the residents and to regulate the violation of traffic rules.

Kigali provides both public and private health centers, as well as three district hospitals and three tertiary referral hospitals. Travel distances within Kigali are fairly short, however, journeys for individuals needing emergency care who are transferred from suburban health centers to referral hospitals can be long and complicated (67). Within each neighborhood, three community health workers should be active, with one responsible for reproductive and maternal health.

Three hospitals were included in this study: two districts hospitals and one tertiary referral hospital. The two district hospitals cover a sample of health centers, from where they receive patients needing further management. The tertiary hospital receives patients from the other hospitals when they are not equipped to manage the care needs. The tertiary hospital is also a University Teaching Hospital, where future medical doctors, nurses and midwives, and medical specialist are trained. At the time of the study, specialists from the United States, through the Human Resources for Health project, were present in two of the hospitals to train and supervise staff.

Healthcare providers working within maternal care in the district hospitals were nurses and physicians (mostly general practitioners) and several registered midwives. One of the district hospitals is responsible for the management and care of the highest number of childbirths per year of any health facility in the country.

A pregnant woman in need of care or in labor should primarily seek care at the nearest health center. Prior to her admission, payment is usually required. Exception should be allowed for a woman in labor, or for other emergencies. In all the three hospitals, the maternity ward provided inpatient care to women for post-abortion, pregnancy and post-natal care.

Context-specific concepts

Some context-specific concepts will be used throughout this thesis, and thus should be clarified. These concepts will be used in accordance with how they are used in Rwanda:

Maternal care in this thesis refers to care during pregnancy (post-abortion care and antenatal care), childbirth and the post-partum period.

Biomedical care refers to care provided within the health system, also referred to as ‘formal care’ in Paper I.

Traditional medicine refers to medicine, therapies and practices not included in the ‘formal’ health system (53), provided by traditional practitioners/traditional healers (94).

Data sampling methods

Prior to starting data collection, the medical anthropologist on my doctoral supervision team trained me in interview techniques in Sweden, and also spent two weeks in Rwanda to train the interpreters and me in how to conduct focus group discussions. Both of the interpreters who worked with me during data collection had prior experience of conducting in-depth interviews. Four pilot individual in-depth interviews (IDIs) were conducted, by the interpreter and me, to evaluate the preliminary interview questions. All interviews followed a semi-structured guide, which was revised prior to each interview and written down on a paper. After each interview we debriefed and reflected on the various aspects captured during the interviews, and wrote down detailed notes. In the beginning of the study, the interpreter translated the interviews word-by-word in the interview situation, which detracted from the natural flow in the dialogue. We therefore decided that the interpreter would summarize the key points during the interview. Probes of interest were discussed prior to each interview, and the interpreter was well informed about the purpose of the study. The interviews that were conducted in English were transcribed by me. Interviews not conducted in English were transcribed by the interpreter together with me, by the interpreter alone, or by an external translator.

Under the section “Reflections on Methods and Ethics” below, I will further describe the composition of the research team and how our various positions and competencies came to influence the study process.

Interviews

Throughout this study, IDIs, smaller group discussions, focus group discussions and participant observations were conducted. IDIs provided an opportunity to privately reflect on matters, and also a forum to talk about intimate aspects (129). The smaller group discussions (GD) with 2–3 participants provided an opportunity to reflect on a topic together with a group of friends, and three of these were conducted with men. Such sessions resemble a ‘natural group’ and is an approach supported when choosing to have more informal discussions with people who already know each other (131). The focus group discussions (FGD), on the other hand, provided an opportunity to discuss a topic with a bigger group, with members who were not necessarily familiar to each other. These discussions resemble more formal discussions and facilitate the process of identifying social norms within a group (132). The extent to which a focus group discussion should

be structured and organized has been the topic of much discussion (129,131). In this study, the FGDs were monitored with the aim of creating a discussion between the participants. The FGDs with women only and those with a mix of genders were monitored by the interpreter. Meanwhile, I observed and constructed probes with an external female interpreter by my side who translated simultaneously. The FGDs with men were monitored by a medical doctor, either the pediatrician involved in our research project or an external obstetrician.

Participant observations

Participant observations were performed throughout the study period, in the hospital setting in general, and while following the participants during the interview sessions. In addition, observations were made of everyday life in Kigali. At the hospital, I participated in twelve morning meetings and three teaching seminars for prospective physicians and midwives, which took place at the three hospitals. I also had the chance to follow a group of midwife students, and spent time with them while they were completing their internship at various health centers. Together with them, I participated in one childbirth and a number of antenatal care consultations. During these observations, I was ‘hanging out’ as a passive observer, thus did not take an active role as a member of any group (131). The aim of performing the observations in the hospital setting was to enrich my understanding of the clinical setting, and to complement the interviews by formulating interview questions and performing member-checks of the findings. A *field journal* was kept throughout the research process. These notes were essential to enrich the recall of certain events, and were also integrated with the analysis.

Member-checks

Member-checks were conducted throughout the periods of data collection to validate interpretations about ‘what was going on’. Lincoln and Guba (1985) stress that no data should be included if they have not been member-checked. This is seen as essential to ensure that the interpretations made by the researcher are verified by the context. Member-checks were completed not only during interviews but also through observations and informal conversations. Topical saturation was considered fulfilled when a phenomena was repeated and validated by several participants’ experiences and perceptions (125).

Triangulation of the data was ensured by using the different methods of IDIs, GDs and FGDs, conducting some interviews at the hospital, in the participants’ homes or in other locations. It was found that interviewing participants twice was valuable (125).

Inclusion criteria for near-miss events

The near-miss approach was chosen to capture women who had nearly died, in order to explore particular barriers to survival in this setting. The near-miss criteria were decided together with local obstetricians, corresponding with the WHO definition of near-miss events (23), and criteria used earlier in other low-resource contexts (24,39). The identified and included clinical criteria were:

- Shock
- Emergency hysterectomy
- Uterine rupture
- Hypertensive diseases: eclampsia and severe preeclampsia
- Sepsis or signs of severe infection (temperature $\geq 40^{\circ}$ C)
- Blood transfusion (adapted to ≥ 3 units of blood)
- Severe anemia (hemoglobin < 6 gram/liter)

The classification of early and late stages of pregnancy was defined by the week of gestation, with “late stage of pregnancy” being at any time point after the completion of the 28th week of gestation. The limit of 28 weeks of gestation was chosen because this is the cut-off gestational age for fetal viability in this setting. The gestational age, and whether the near-miss was considered to have arisen upon or after arrival, were decided by the physician, midwife or nurse in charge.

Recruitment and participants

‘Near-miss’ women – Paper I

For Paper I, women who experienced a near-miss were purposively recruited at the three hospitals included in this study. The near-miss women were identified at each hospital by the research team in collaboration with local obstetricians, midwives and nurses. During the first three months of data collection, my interpreter and I went every weekday for a ‘round’ to the three hospitals included in this study to recruit near-miss women. After this initial period, these recruitment rounds were completed less frequently over the following three months, and after that we focused on follow-up interviews. Sometimes a healthcare provider informed us of new near-miss women via telephone. We (usually the interpreter and me, and sometimes the interpreter alone) approached each identified woman some days after the near-miss event, explained the study objectives and asked whether she wanted to participate. Not all women who we approached agreed to participate. The interviews were conducted in their hospital room or in a private room, and occurred within the first week following the near-miss event.

The women were contacted for a follow-up session within nine months after the initial interview if they lived within two hours of Kigali and had given consent to be contacted again. We revisited 14 of these women, who were interviewed either in their homes or in a restaurant that had a private room. Seven of the women who were interviewed in their homes were interviewed together with their partner.

Each first-round interview took approximately 20–60 minutes, and each second-round interview lasted 60–120 minutes. All except one were audio recorded. The first IDIs always started with the question: “*Can you please tell us what has happened?*”, and usually the women started from the beginning, how they found out they were pregnant and how they had ended up at the hospital. The conversation was guided by probes and questions to cover the themes of care-seeking during pregnancy, uptake of antenatal care, experience of pregnancy, the symptoms and complications that arose, and of the care provided during all phases. The follow-up interviews focused on the period after the near-miss and family planning, and revisited the questions of experience of care. In cases where a partner was present, we were cautious about discussing sensitive topics. However, interviewing the couples together was taken as an opportunity to also observe the dynamics of their relationship.

The women were between 16–38 years old. All except five women belonged to the lower socioeconomic group and were thus eligible for the community-based health insurance scheme. They represented a varied group in relation to their age, level of education and number of children. All of the participants expressed their religious beliefs, with the majority being Christian, and some, Muslims. Most of the women lived within or closely outside Kigali, and several were from rural settings, as they had been referred to the hospital. Several of the participants were unemployed and expressed limited affordability of care if uninsured. Not all women were covered by community-based health insurance. The women were either in a relationship, which included being married or in a registered partnership, or single. Women who were single included women who had recently separated, either during or as a result of the pregnancy. Some of the women described having experienced physical or sexual abuse from their current or former partner, and one woman claimed that her miscarriage was a result of physical abuse.

‘Near-miss’ women, their male partners and community members – Paper II

For Paper II, which explored the perspectives and experiences of antenatal care and partner involvement, we included the IDIs conducted with women with a near-miss experience and their partners, as well as 3 GDs (*referred to*

as FGD in paper II) and 5 FGDs (Table 3). The participants were recruited in a snowball strategy via the near-miss women or men, who also participated (131). Our interest in exploring community perceptions of antenatal care emerged as we identified that few of the single women had sought antenatal care.

Table 3. *Overview of participants and type of data collected in Paper II.*

Participants	#	Type of data collection	Place and Time	Included in
Men: Partners to MNM & Community members	8	3 GD	Participants' home April 2014	Papers II & III
Women: MNM & Community members	17	2 FGD	Conference center Nov 2013	Paper II
Mixed: Women & men MNM Community members	24	3 FGD	Conference center Nov 2013	Paper II

These FGDs covered the topics of: experiences with antenatal care; attitudes about and understanding of the current antenatal care guidelines; and perceived disincentives to meet antenatal care recommendations, as well as perspective on male involvement during childbearing (*unpublished material included in this thesis*).

The characteristics of the women with a near-miss experience are presented above (*Paper I*), and the men, below (*Paper III*). The female community members covered an age span of between 21–52 years, and the male community members 21–62 years. Most of the participants lived in the suburbs of Kigali. Almost all had completed primary level education, and some had completed secondary or higher. Not all women were covered by the community-based health insurance. Some were covered by an alternative insurance scheme, and several were uninsured. The most common professions were daily wage-earners or smallholding farmers. Several were unemployed and expressed having limited affordability of care, particularly if they were uninsured.

Recent fathers and partners to ‘near-miss’ women – Paper III

The partners of women with a near-miss, included in Paper III, were asked to take part in this study after their partner had given their consent. Nine of them were interviewed at the hospital. Four men were interviewed together with their partners in their homes, as well as three of the men who had already been interviewed. To elaborate on the men’s perceptions of their role during pregnancy and childbirth, we asked all nine of these men to bring two or three friends for further discussion, which resulted in three GDs and three FGDs. An overview of the data collection relating to the men is provided in Table 4 below:

Table 4. *Overview of participants and type of data collected in Paper III.*

Participants	#	Type of data collection	Place and Time	Included in
Partners to MNM	9	IDI	Hospital, private room, 2013	Paper III
Partners to MNM	4	IDI, with MNM partner	Participants’ home, 2013	Paper III
Partners to MNM + Community members	19	3 FGD	Conference center, Nov 2013	Paper III
Partners to MNM + Community members	8	3 GD	Participants’ home, April 2014	Papers II & III

All interviews covered topics relating to the men’s perspective of their role during pregnancy and childbirth, on the use of contraceptives, desired number of children, and their perspectives on maternal care within the public health system and the community-based health insurance program. In these interviews, men often raised issues they wanted to reflect upon, particularly regarding the quality of care and the interaction with providers.

The men were between 23–35 years old, and two were in their fifties. They had either primary or secondary level education, except one, who was currently studying at the university. The men had varied occupations, with several being daily wagedworkers and some unemployed. The men represented the lower, and lower-middle socioeconomic group. Four of these men’s partners had had a miscarriage and three of their babies had not survived birth, and two men had prior experiences of a baby not surviving birth.

Healthcare providers – Paper IV

The healthcare providers (HCP) were purposively recruited from the three hospitals as well as through snowball sampling. The interviews were conducted between October and December 2013 and March and April 2014, with a final member check session conducted in March 2016. In total, 32 IDIs and 5 FGDs were conducted. The latter consisted of 3–6 participants

each. The interviews were mostly performed in English, and therefore, I was able to conduct these myself. A few were conducted in Kinyarwanda together with the interpreter. The IDIs lasted between 30 and 70 minutes, and the FGD between 90 and 120 minutes. All except 2 IDIs were audio recorded. Most IDIs were completed at the hospital, except seven, which were conducted in the participant's home or at a restaurant. The FGDs took place at a restaurant where we could use a private room. The interview guide covered aspects of quality of care, perceptions and attitudes towards abortion, post-abortion care and contraceptive counseling, and reflections on the current abortion legislation and guidelines, as well as quality of maternal care.

In total, 52 HCPs participated: 19 physicians (2 registered OB/GYN, 5 residents doing their specialization in OB/GYN, and 12 general practitioners) as well as 24 midwives and 9 nurses. The healthcare providers were between 21 and 53 years old and presented varying degrees of experience. While some were permanent staff, others were temporarily employed, had just finished their studies, or were doing their internship at one of the three hospitals at the time of the interview. The participants had at least 6 months of clinical experience within maternal wards, including in other hospitals, and/or public or private health centers. The majority had between 1–4 years of experience, while several had worked between 10–15 years. Notably, some participants had been assigned to study their given profession, which may also have affected their standpoints. The HCPs shared vivid experiences of meeting women who sought advice prior to, or care after, a voluntary, and mostly unsafe, induced abortion, and who were often admitted with already hazardous complications. All HCPs were, or had been, involved in providing post-abortion care. Although the participants narrated comparable experiences, they presented distinct attitudes to induced abortion and approaches to counseling.

Data Analysis

Because the framework of naturalistic inquiry guided my data collection, part of the analysis started on the first day of fieldwork by identifying patterns and defining new questions to test the preliminary findings. The analysis of naturalistic inquiry is interpreted as being twofold – data analysis conducted on-site, and data analysis conducted off-site (125). Once all of the interviews were transcribed, in-depth analysis was conducted off-site, using separate methods, depending on the aim of the separate papers.

Naturalistic inquiry as analysis method

The method of naturalistic inquiry (125) is a flexible approach, with an emphasis on constant comparison of the data. Naturalistic inquiry lays out two main steps for analysis: unitizing and categorizing. The process of unitizing is a process of sorting, and then coding the sorted extracts. This can be done manually or by using qualitative data analysis software. I did it manually, by printing out the transcripts and cutting out the relevant sections and then coding these pieces of paper. The next step is categorization, where similar codes are grouped together in piles. In this stage, similarities and differences will be noted, and these can form new categories.

In Paper I, a deductive approach was used for sorting and the initial coding by using inspiration from Thaddeus and Maine's (1994) 'three delays' model: Phase I, decision to seek care; Phase II, identifying and reaching the medical facility; and Phase III, receiving adequate and appropriate treatment (133). Together with one of the co-authors, we created a matrix with separate columns for early and late stages of pregnancy, and devised color-codes for marital status, to indicate whether the near-miss arose prior to or on arrival at the facility, and whether care had been sought repeatedly. Field notes were integrated into this matrix on observations taken about each woman, as well as notes from informal conversations on traditional medicine, and observations at the hospital relating to shortages in the referral system. We thus expanded the framework, and also allowed for codes outside of the 'three delays' model. When comparing the overall similarities and differences within the women's narratives and field observations, we noted resemblances and contrasts in trajectories and experiences of care, and also distinctions that did not follow the three-delay trajectory. We identified four overarching categories to capture these, and discussed these with the other co-authors.

For Paper III, I unitized the data and identified preliminary categories. These were then discussed with one of the co-authors. I re-read the transcripts and re-coded part of the material. To sort all the codes, I found it useful to sort my findings into the conceptual framework inspired by Connell (134) to separate and further analyze differences and similarities on intrapersonal, interpersonal, institutional and societal levels. When these were determined, and discussed with the co-authors, I re-read my transcripts and notes yet again, and also presented and discussed my interpretations with two laymen in Rwanda to validate my interpretations.

Framework analysis

During the fieldwork the aspect of antenatal care gained increased interest, particularly as the perceived policy of male attendants and an optimum of four visits was repeatedly criticized. Therefore, for Paper II, framework analysis was chosen, as it is an appropriate method for identifying the “bottom-up” perspective in relation to policy. There are several different types of framework analysis, and we chose the type described by Ritchie and Spencer (1994) and Srivastava and Thomson (2009) (135,136). All relevant data, incorporating field notes, were coded deductively by using concepts drawn from the current Rwandan antenatal care guidelines, such as ‘attitude to partner involvement’. I used ATLAS.ti (Scientific Software, 2013) for coding and extracted the coded sections of my material. These coded sections were then mapped and interpreted by constant comparison between each other and the relevant antenatal care guideline. In discussion with the co-authors, we identified conflicting perspectives between the guidelines and narratives provided by the participants. These were interpreted as paradoxical barriers. After this, I returned to the transcripts to re-read and reflect on consistency or disagreements. I identified three main themes, which were once more discussed with the research team.

Thematic analysis

For Paper IV, thematic analysis as described by Braun and Clarke was applied to the data (137). This method provides a rather systematic approach for identifying and analyzing patterns. The transcripts were read through two times prior to coding as a substantial amount of time had passed since the data had been collected. The transcripts were coded, and the coded extracts and notes taken were organized manually into an Excel spreadsheet. Codes were sorted into a thematic map to identify similarities and differences. When this analysis took place, gaps in the data were identified. Two additional focus group discussions were therefore conducted in March 2016 to reach topical saturation. These data were coded, and the other transcripts revisited, and all were added again to the Excel spreadsheet. Data were again sorted into a thematic map and themes were redefined. These themes were then revised when writing up the findings section, in discussions with the co-authors.

Reflections on Methods and Ethics

In order to ensure the trustworthiness of the data, that is to say, its credibility, transferability, dependability and confirmability, Lincoln and Guba (1985) argue that the researcher must engage in critical reflection about the ways in which the research has been carried out (125). This involves taking responsibility for ensuring that all steps of the research process are carefully explained; it is only by doing so, many claim, that readers and other scholars can validate the correctness of the interpretations that are being proposed (see Skeggs, 1997) (138). In the chapter so far, I have sought to address many of these demands by providing detailed accounts for, for instance, data collection methods, participant characteristics, and analyses of data. In addition to this, however, Guba and Lincoln are of the opinion that further reflections must be provided regarding how I, as a researcher, may have influenced the research process in various ways (125). One's 'positionality', in this respect, refers to the particular position in relations to others, and usually concerns culture, ethnicity and gender (139). Moreover, one's position as a researcher requesting to gain knowledge about other people's – sometimes very private – life perspectives, may evoke several ethical questions about how to proceed or deal with matters at stake throughout the research process. In the following and final section of this chapter, I will seek to address some of the methodological and ethical challenges that I have faced during this course of study.

Research team and cross-cultural relationships

This research project is a continuation of a joint partnership between Uppsala University and the National University of Rwanda. I was guided by a multidisciplinary research team composed of: two medical doctors, a pediatrician and an obstetrician, both men from Kigali; and three European researchers, all women, an obstetrician/gynecologist, a midwife and a medical anthropologist. All have obtained a PhD.

All interviews in this study were conducted by me, or in my presence together with the study interpreter. My educational background lies in social work and global health. My interests in sexual and reproductive health and rights, and gender equity, certainly influenced the route that this project took. Prior to being involved in the study I had not visited Rwanda, but I was familiar with many of its socio-political issues and accompanying debates, particularly those gained during my studies in global health. I have spent a total of 10 months in Kigali over the last four years, which has helped me to 'ground' myself in the setting (125).

As a foreigner to the setting, not able to speak Kinyarwanda, I was dependent on an interpreter for most interviews. During the project, two different interpreters were used. The first interpreter was a 30-year-old married woman, mother of two, who was born in Uganda but who had Rwandan origins, and who was a midwife by profession. She had experience of working on previous qualitative research projects. Her profession, being a midwife, facilitated the process. She knew the system at the hospitals and could translate medical terminology that was new to me. She also knew many of the hospital staff. The rest of the interviews were conducted with the second interpreter, a woman in her late twenties from Kigali, who was unmarried and without children at the time of the study. She also had experience of working on previous qualitative research projects. The interpreters also performed the role of research assistants.

Peer debriefing was an important part of the process both during data collection and analysis. A dialogue was kept within the research team throughout the study period. The research was also presented in seminars that took place in Sweden, and at a number of international conferences, to receive feedback and to gain reflections on the findings from professionals outside the context.

Reflections upon positionality

Prior to initiating the data collection, I spent three weeks in Kigali to get to know the setting, and reflect upon the broader focus of the project. Rwanda is argued to be a country “full of paradoxes, difficult for outsiders to comprehend and to apprehend” (140), a statement that I can agree with. Throughout this process, some key persons were essential for me to allow me to reflect and enrich my understanding of the cultural and political aspects in this setting. I tried to keep a “double hermeneutic” in mind to not take things for granted, but to question my interpretations, and also how I may have influenced the answers I obtained (141).

To be dependent on an interpreter can be seen both as a limitation and strength. The interpreters were essential in guiding me in the Rwandan setting. Many were the discussions about norms and customs, gender roles and motherhood in Rwanda, and similarities and differences to Sweden. While the collaboration with the first interpreter worked well in the beginning and her profession as a midwife was an asset in navigating the system, I took the decision to change interpreters. This was decided after I sensed that she rephrased some of the questions, and the interviews did not reach the depth I aimed for. I double-checked some of the transcripts with an external translator who confirmed that some questions were rephrased. All of these interviews were double-checked, and were still used in the analysis. The interviews conducted with the second interpreter, however, were more

in-depth, highlighting the importance of the interpreters' role when conducting qualitative research. Throughout the research process I maintained a constant dialogue with her to reflect upon the interview answers and preliminary findings in the data (141).

An essential aspect during data collection was to earn the participants' trust. An aspect worth considering was that we had to wear 'white coats' in the hospital setting. This often made the participants perceive us as healthcare providers from the specific hospital. When asking potential participants we always explained that we belonged to a research team that was not a part of the hospital. We also took the coats off during the interviews, and explained again that we belonged to a research team. It may be that some participants still perceived us as healthcare providers from the specific hospital, which may have affected their responses. The interviews in the participants' homes were often more relaxed, which may have been a combination of the setting, and that they were meeting us for the second time. To build trust with healthcare providers was a different process, as all spoke English well enough for us to have a conversation. This also highlighted the difficulties in communicating through an interpreter, which could be frustrating at times.

Another aspect that I came to reflect upon a lot was my positionality as 'white', which was clearly associated with a position of privilege. The color of my skin often drew attention to me, particularly in situations when I visited participants in their own neighborhoods. This also brought attention to the participants. The participants often expressed gratitude to us for having visited them, and we often sensed that they seemed proud when their neighbors learned about us visiting. However, we always asked beforehand whether they preferred to be interviewed in their homes or at another location. On one aspect, the attention we brought may indeed cause an ethical dilemma. In the interview situation, my positionality of being a foreigner was interpreted to bring openness. Other researchers conducting interviews in Rwanda have also brought this up, reflecting that people may feel that they are in a safe space and are more likely to open up to someone who is not Rwandan (58).

Methodological dilemmas

To minimize potential mistranslations and to ensure validity, we double-checked all of the transcriptions (apart from the ones carried out by me and the interpreter together) with an external translator. In the beginning, the transcripts were carried out by the interpreter and me, or by the interpreter herself. Although this was a useful way to reflect on the interview, it was time consuming. To facilitate the process, we asked two students in English, and one translator, who were known to the interpreter, to assist us with the

transcripts. They were informed about confidentiality. However, when our interpreter double-checked some of the transcripts, it occurred to us that pieces of information were missing. We therefore asked a professional translator to double-check all the transcripts that had been carried out so far. After this, the professional translator would translate and transcribe all interviews, and my interpreter and me would double-check them together.

Social desirability may always be present in an interview situation, yet depends a lot upon the questions posed (131) and we attempted to overcome this by asking open-ended questions, probing, and conducting member-checks.

Ethics considerations

Ethical approval was obtained from the Rwanda National Health Research Committee, Kigali (NHRC/2012/PROT/0045) and the Institutional Review Board of Kigali University Teaching Hospital. Permission to recruit participants was sought and obtained separately from each hospital. Hospital staff were informed about the research project and the reason for our presence.

All participants were informed that their participation was voluntary, and that they had the right to withdraw from the study at any time without providing any reason. They were also informed about confidentiality and were assured that their individual data would be kept confidential and that any quotes they provided would remain anonymous. Verbal or written consent was attained before initiating each interview, and these were audio recorded if we had obtained permission. We ensured that the audio recordings were kept secure and that the transcripts were anonymized. Permission to use the participants' answers for anonymous quotation was also sought and obtained. During the interviews we provided all participants with refreshments and covered the cost of transport if the participant had to travel to take part in the IDI or FGD.

We made sure all women with near-miss events were interviewed only after they felt comfortable being so. The interviews were stopped as soon as the women wanted to rest, which was the case in a small number of the interviews. Given the traumatic experiences that one may have during a near-miss, or as an eyewitness, the interview may awaken unpleasant memories and feelings (142). To take this into consideration, we always asked the participants after the recorder was switched off whether they had additional questions or concerns, which several participants had. We made sure that all of their questions regarding the project were answered, and that participants with questions and concerns regarding medical queries were put

in touch with a medical doctor at the facility or a medical doctor involved in the project. On a few occasions, other concerns arose and we then connected the women with a social worker, or to other organizations that we knew of who could provide help. All participants received our contact information in case any concerns might arise afterwards, and several participants did contact us.

Interviewing the women at the health facility made it possible to meet them shortly after their near-miss experience, which facilitated their recall of the event. In a few cases, we were also able to capture the insights of women who live in remote areas outside Kigali, as they had been transferred to one of the hospitals. However, when conducting interviews at the health facility it appeared that women often were hesitant about sharing their experiences of the care that they had received. Therefore, we adapted the interview guide and focused more on the aspects of care-seeking when the women were interviewed at the hospitals, and asked them about their experience of care when we met them on a separate occasion away from any health facility. Given the sensitivity of the subject of abortion and pregnancies that did not come to term, we were extra cautious to ensure privacy throughout these interviews. For all interviews, we made sure not to press the women for answers, but to let them describe their experiences at their own pace. The necessity of building up trust is important, which was perceived as being gained to a higher degree during the second interviews with each participant.

Conducting FGDs raises an ethical dilemma in ensuring that all participants maintain the confidentiality of each other's thoughts and experiences. Prior to each FGD the aspect of maintaining the confidentiality of the discussion was emphasized. Some participants shared sensitive aspects, and in the FGD with healthcare providers, personal viewpoints relating to abortion were revealed. What usually happened in these situations was that others also felt comfortable in opening up.

Conceptual Frameworks

The Three Delays Framework

To conceptualize delays in seeking, reaching and receiving care, the ‘three delays model’ (see Figure 2) by Thaddeus and Maine (1994) was used both in designing the research questions and sorting the data. This framework has been used extensively in research focusing on maternal health, as well as research considering the near-miss approach specifically (34,143–147).

In brief:

Phase I: Decision to seek care is influenced by the perception of the actual need for treatment: perceived etiology; perceived severity; educational status; ability to pay and reach the facility; and a woman’s status and dependency on others. The decision is also influenced by the interplay of social others, potential socio-legal sanctions, preference of treatment and the experience or perception of the quality of care at the reachable facilities.

Phase II: Identifying and reaching the medical facility is influenced by physical distance, transportation, the distribution and location of health facilities, the health system infrastructure, and the ability to pay.

Phase III: Receiving adequate and appropriate treatment is dependent on the available equipment and the receipt of prompt and quality care by skilled healthcare providers, and patient-provider interaction.

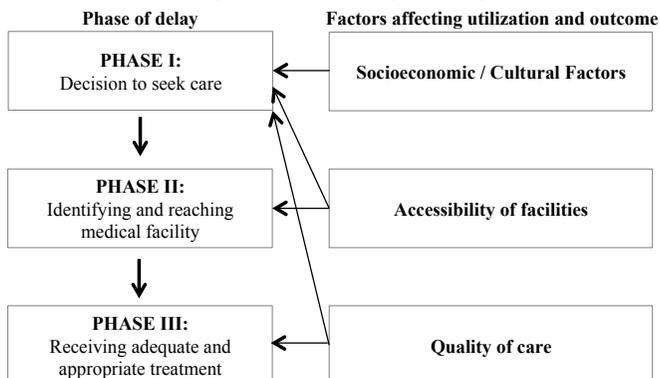


Figure 2. Conceptualization of the three delays according to Thaddeus and Maine (1994).

Bottom-Up Approach to Policy Implementation

At the initiation of this project, a policy perspective was not anticipated. However, throughout the progress of the research, policies were found to be central to the narratives of the participants. In order to conceptualize the gaps between policy and practice, the ‘bottom-up approach to policy implementation’ is used.

Policy can be defined as a broad statement of a goal or objective, meant to create an agenda for activity. Policies are usually explicitly stated in writing, but may also be implicit, or unwritten (148). Implementation can be defined as “what happens between policy expectations and (perceived) policy results” (149). That policies do not always work out as anticipated, which is a well-known circumstance, is a phenomenon referred to as “implementation gap”.

Currently, the bottom-up approach is advocated to identify potential implementation gaps which curtail the work of improving maternal health (16). In contrast to a top-down approach, which usually takes the analytical standpoint from the government’s position (150), the bottom-up approach is important for bringing forth the local knowledge of a setting (151). To conceptualize policy implementation from the bottom-up, the *structural factors* of a society, such as the political system, the demographic aspects and technological advancements, must be considered, as well as the *cultural factors* within, for example, the norms, religious factors and gendered roles and expectations (148).

The bottom-up approach sees policy implementation as complex, non-linear and interactive, involving ‘implementers’ at various parts and levels of the system. Implementers are thus active in the realization of the policy. Therefore, these implementers’ own views and anticipations influence the outcome of the policy. In health policy, the ‘implementers’ are usually staff working within a health system (148). Lipsky’s (2010) theory of ‘street-level-bureaucrats’ is frequently used within the bottom-up approach to bring increased understanding to the complexities that implementers face in the realization of policies and regulations. This theory originates from the ’80s, and has been used to understand policy implementation from the perspective of, for example, social workers, police, teachers and nurses (152–154). The theory informs how decision-making is seldom bound to the rules and regulations. Instead, decisions are usually taken in negotiation between personal values, the demands and limits of rules, as well as the socio-cultural context and norms in a setting, and the uniqueness of each client–provider interaction and meeting. Therefore, it is important to take these

implementers' perspectives and experiences into account, and to inform and include them in setting guidelines that are of concern to their work (155).

The strength of the bottom-up approach is in its possibility to inform about the challenges that are faced by the implementers and users at a grassroots level, how it affects the users of this policy, and to illuminate how a policy may work out in practice. It will be used as such for the purpose of the discussion section in this thesis.

Main Findings

The main findings of this thesis are presented under two headings, each of which include a summary of the findings for all four papers as well as unpublished material (marked explicitly). For further details of the findings, see the reprints of Papers I–IV appended to this thesis.

Barriers to Maternal Care

Criminal label on abortion

Among the women who experienced near-miss, both in early and late pregnancy, the unmet need for contraception was a common theme, particularly among the young and/or unmarried women. The women presented varying reactions to their pregnancy, with some defining it as unintended or unwanted. The routes taken varied from neglecting the pregnancy, keeping it secret or wishing it to terminate spontaneously – to either “coming to terms with it” or taking action. The decision had usually been taken by the woman herself in private, or after consulting a trusted confidante. For one woman, the abortion was a result of physical abuse by her partner. No one had sought a legally induced abortion or knew of this possibility. Women’s actions varied from turning to a traditional healer, going to a clinic offering this service clandestinely, or handling it themselves, for example, by the insertion of a cassava stick. One woman described:

I got two cassava sticks, went to the toilet and inserted them deep into my vagina. I hated myself in that moment, but I was reasoning that since my parents are dead, and I don’t have a husband, I would not have been able to take good care of that baby. So, I felt like the best option was to abort that pregnancy.

29-year-old, ‘near-miss’, *Paper I*

Advice or care for symptoms, such as bleeding, in early pregnancy was sought with hesitancy. This seemed particularly prominent among single women. Meanwhile, married women presented less hesitation, and perceived that they were protected from suspicion and stigma from the community.

Most of the single women with a near-miss in early pregnancy had actively tried to hide the pain and/or bleeding, and had been found in a critical condition by a family member or neighbor, and brought to the facility for care.

Delays in receiving treatment for early pregnancy complications were identified. One of the near-miss women was advised to return home when she sought care after an abortion: “the nurse told me that since I had aborted I didn’t need to go to the hospital” (24-year-old, ‘near-miss’, *Paper I*). The woman’s condition had worsened, and she was referred to the hospital in sepsis, with the result of having one of her fallopian tubes removed. Another woman described how a doctor at a private health clinic had refused to help her, following what she described as a miscarriage:

I started to bleed so much. I wanted to rush to the closest clinic, but when I got out of my gate I felt dizzy and a moment after I fainted. Some of my neighbors got me up and brought me to the clinic. When I got in the doctor said he wasn’t going to do anything without my [partner] also being there. My boyfriend kept calling and speaking to the doctor because he couldn’t be there in that sudden moment. He begged them to do everything possible to save my life. But the doctor did not act, and told me that the referral hospital would report him for an illegal abortion. He said he can’t do anything because they always shut down his dispensary.

24-year-old, ‘near-miss’, *Paper I*

The woman reflected that the healthcare provider refused to treat her as a precautionary measure because he was trying to avoid being accused of having performed an abortion. However, the criminal label of abortion also placed suspicions on some of the women as being responsible for causing the symptoms, or the abortion itself. One 16-year-old woman was investigated by the police after a neighbor had reported her, suspecting that she had induced the abortion. Others described that they had lost their jobs or been left by their intimate partner, for example:

When I told my boyfriend that I had lost the baby, he thought I was the one who voluntarily aborted the pregnancy. I asked him: “Can you imagine how I felt lying in a hospital next to women who had had abortions? Do you think I was happy?” But he didn’t believe me. I have not seen him since.

26-year-old, ‘near-miss’, *Paper I*

Fear of litigation

The healthcare providers included in this study presented varying attitudes towards the current abortion law, and not all were aware of the amendments and allowance for induced abortions under certain circumstances. Despite these legislative amendments, nothing was identified as having changed in practice. Induced abortions were perceived as a taboo topic in the society, which also brought hesitancy among healthcare providers to be associated with induced abortion and related care. A combination of factors related to these misgivings seemed to be the contradiction of personal values and fear of stigma and/or litigation. A prominent rationale for this disfavor for legalizing abortion was the threat it would pose to one's occupational identity within the community. One midwife said: "If abortion is legal it will be a problem. People will be like 'this one is a killer because she did abortion to mothers or to girls'" (Midwife, woman, *Paper IV*).

Healthcare providers working in post-abortion care distanced themselves from the topic of abortion. Misoprostol was noted to be fraught with controversy as it could be used to induce abortions. The controversy was problematized, as it seemed to restrict the availability of the drug, particularly at the health center and community level. It was also an aspect that could potentially cause rumors to develop between colleagues. One midwife explained how insinuations were made at her previous workplace:

We had a doctor who would sometimes ask for [misoprostol], and even if he needed it to provoke someone's contractions, people would start gossiping that he was going to perform an abortion.

Midwife, woman, *Paper IV*

There was a lack of consensus on care providers' juridical responsibility to report a woman to the police if her illegal abortion was disclosed. Healthcare providers reflected that the criminalized status of abortions, and women's fear of litigation, contributed to women's delayed care-seeking, or posed hurdles to prompt treatment, as women were sometimes reluctant to disclose how the abortion had actually happened and whether it had been spontaneous or induced. One man reflected:

[Women] don't want to come [to the care facility] immediately as they fear to go in prison. I think that when it is legal, people will not be ashamed to come here immediately, and this will also reduce those [post-abortion] complications

Nurse, man, *Paper IV*

The healthcare providers emphasized the need to adhere to the professional code of ethics by ensuring the confidentiality of a patient. However, they expressed that ‘other’ healthcare providers may not adhere to this. Ensuring confidentiality seemed to be challenged in situations where police asked them to determine whether an abortion was spontaneous or induced. One younger physician also explained that his clinical superior had informed everyone during a morning meeting that, “regardless of anything else, we must tell the police that she aborted voluntarily – if she did” (MD, man, IDI). In addition, healthcare providers could also be subject to litigation, which seemed to make them cautious about providing advice or in expressing their position on abortion. One nurse said:

Sometimes it is a trap that the police use in order to arrest a doctor who has been rumored to help people to get abortions. They are going to bring this girl to you and you will help her and three days later the police will be at your door and you will end up in jail.

Nurse, woman, *Paper IV*

Antenatal care requires male attendant

Both women and men were well aware of the recommendation to attend antenatal care four times, and either perceived or experienced it as an obligation to be accompanied by a male partner for the first visit. If a partner was not available, the described alternatives were to either obtain an official document from the chief in the neighborhood containing information about the partner’s inability to attend, or to ask another man to pretend to be the father of the coming child. This requirement was perceived as causing delays in seeking care, discriminating against single mothers, or causing women to not seek antenatal care at all. As no identification of the partner was required, it was possible to attend with someone else:

When I was [at the health center], a woman came for her medical check-up and she waited for her baby’s father for hours and he didn’t show up. People told her to just go outside and pay one of the guys who were idling on the street and ask him to come with her as the baby’s father. She went and paid the guy, and he came with her and they got the check-up over with.

34-year-old man, *Paper II*

Attending antenatal care was perceived to facilitate admission for childbirth at a public healthcare facility without being fined or punished. The obtained antenatal care card, denoting the HIV status and confirming the four required visits, was perceived as an ‘access pass’ by the women.

Financial constraints

Antenatal care was supposedly provided free of charge, yet the financial burden appeared to be a reason for delayed attendance, or no attendance at all. A document proving insurance coverage was perceived as being necessary to be able to receive antenatal care, and thus many women delayed seeking care until that was arranged. The requirement for a male to attend the first visit also caused delays that were grounded in financial matters. Taking time off work was not always feasible, particularly if the work was based far outside the city. Long queues and inefficiency at the clinics were also perceived to take away valuable time for the woman and thus, indirectly, her income.

When seeking care for childbirth, a shortage of money, not being covered by insurance, and/or having no support from the partner or a female relative or friend, were reasons for delayed care-seeking. It was perceived as mandatory to give birth at a care facility, and reaching the nearest facility on time was a motivating factor to avoid fees. Despite explicit support in the policy for giving birth at a facility, this fining system was questioned. One man described a common strategy in cases where a woman would give birth at home:

You have to keep the umbilical cord uncut and just rush to the hospital, because if you cut it, you will have some issues with the doctors. They are going to fine you. You just need to explain to them that the contractions were sudden and took her by surprise.

28-year-old, man, *Paper III*

However, the ability to pay was presented as important as it was perceived, and experienced, as a possibility that the woman would be kept at the facility until all costs were covered. The reasons that the women provided for wanting a person to accompany them was for someone to ease the admission process, organize the required supplies, provide food and to speak on their behalf if something happened.

The community-based health insurance was claimed as being necessary to manage all costs. Yet, some medicines were not covered by this insurance, which also was a reason for incomplete treatment. One woman had asked to be discharged earlier than necessary because she could not afford inpatient treatment. For others, the need for specialist equipment and emergency surgeries, particularly caesarean sections, raised the costs dramatically and unexpectedly, and at some facilities the costs were to be covered prior to the procedure, which delayed the initiation. It was identified that healthcare

providers sometimes helped out with the expenses. One woman described: “One of them bought me an injection, and another added the amount that was left from what my husband had so we could buy the medicine” (22-year-old, ‘near-miss’, *Paper I*).

Suboptimal provision of counseling and care → repeated care-seeking

Women expressed hesitation in seeking care ‘too early’ and expressed concerns that this was not appreciated among the care providers, either at antenatal care or for childbirth. A prominent obstacle in the care encounter was the poor patient–provider interaction according to the women. At antenatal care visits, limited information was provided about danger signs or risks during the later stage of pregnancy. Early signs were missed in consultations, misdiagnosed or not taken seriously, even though some women had repeatedly sought advice at the health center. A few of the women reflected back and believed that their problems could have been avoided had the healthcare providers paid more attention and informed them of potential complications. One woman who had sought care several times explained:

When I went to the health center they could not do anything for me. They only told me that during the first pregnancy the problems can be like that, with some women sleeping the entire time, and that it was normal to feel sick. I started feeling discouraged, and not able to trust that the healthcare workers could help me. I do not give a credit to health check-ups because they were just treating me as if I was a complainer.

23-year-old, ‘near-miss’, *Paper I*

Another woman had sought care because of pain during early pregnancy, and had been offered an injection and pills to treat her symptoms, but she refused:

I asked him how he could inject me and give me pills without consulting me to be sure about what I had [...] I refused because I didn’t trust those medicines because I thought they could also be harmful to my pregnancy.

25-year-old, ‘near-miss’, *Paper I*

The women who experienced near-miss during late pregnancy also raised complaints about not being listened to by the care providers, receiving inadequate explanations and being spoken to rudely. One woman with earlier experiences of complicated births had actively tried to prevent history from repeating itself but felt overlooked and was met by comments such as: “Who do you think knows what to do here, us or you?” (29-year-old, ‘near-miss’,

Paper I). The men also described such obstacles, and one man whose partner had had a near-miss said:

[My wife] told me that when a woman is still in the waiting room and starts shouting, the [health care workers] will not even glance at her. They say that, “if you can still shout, it means you definitely still have strength.”

33-year-old, partner to ‘near-miss’, *Paper III*

The underlying reasons for the near-miss outcome were rarely explained to the women. Neither had they been informed which symptoms to pay attention to. For some, the near-miss arose after they were discharged, mostly due to retained placentas or other infections developing into sepsis. These women had delayed seeking care again because they perceived the symptoms as part of the recovery process. A preference for other solutions was also raised, or preference to be cared for at a private clinic.

Supportive reasons for traditional medicine

Adherence to the use of traditional medicine was prominent in women’s care-seeking any time during pregnancy, but particularly late in pregnancy, just prior to birth. The medicine was described as a precautionary measure, taken either orally or applied on the abdomen, in order “to get ready” for birth. Other reasons were also described:

I was due but my contractions had not started and I knew that if you go to [the clinic] without contractions, they are not going to help you. My husband bought a small dose of traditional medicine made from herbs. It helped me. If I hadn’t taken that medicine, I wouldn’t have given birth.

37-year-old, ‘near-miss’, *Paper I*

This measure was taken in secret, as it was perceived that most biomedical health facilities would impose a fine if they found out.

They don’t allow drinks though. I remember that there was this poor woman and the people from her family asked me if they could bring her some tea. I thought it was ok so I told them they could bring it. When I got it inside the room, they refused categorically to give it to the patient, saying that they could never be sure about what was in there. They won’t allow any drinks unless it is like soda because it is closed with a cap on the bottle.

28-year-old, ‘near-miss’, *Paper I*

Other reasons for precautionary measures in taking traditional medicine were: “If a woman has been bewitched she won’t die while delivering” (23-year-old, ‘near-miss’, *Paper I*). Witchcraft was referred to as someone

“putting a spell on you” or as “spiritual agents”. Underlying reasons for this were described as jealousy or hatred towards the woman or her family. Witchcraft was also identified as a way of describing the reason for a complication, and thus delayed women in their care-seeking. One woman who had a hypertensive disorder had noticed a change in her pregnancy, but had not sought care:

I have a belief that there is one lady who bewitched my baby inside the womb, because, I used to feel my baby moving, with no problem, but after that lady visited me, my baby died.

20-year-old ‘near-miss’, *Paper I*

Among the women who were not satisfied with the care they had received, or had not been cured, some also adhered to traditional medicine for a solution. Other reasons they provided were that payment for consulting a traditional healer could be paid later or in installments, neither of which seemed to be offered by the public health facilities.

Perspectives on Male Involvement

Limited accessibility to maternal care

The men included in this study presented ideals of being caring during their partner’s pregnancy, and one man stated: “You try to play a role in her pregnancy and you do all you can to make sure she is taken care of” (33-year-old, man, *Paper III*). The supportive reasons for a man to accompany the woman when seeking care, expressed by both women and men, were to facilitate admission for care. However, when it came to the actual consultation, the men had not been included, and waited outside. The men in this study expressed a wish for more information, and to be present at the consultations. A recurrent reasoning was:

[Health care workers] are more interested in talking to the women, but they do not consider informing the men, as well. It would be better if we all could understand more about those symptoms

27-year-old, man, *Paper III*

Both the women and the men suggested that including men in the care encounters would make them respect the advice given to a woman if this was heard first-hand from a healthcare provider. One woman said:

When you go for consultations, they might find a problem and tell you to avoid hard work, but most of the time our husbands do not believe it. It may be that the husband thinks you are lying to avoid work, and he might start treating you bad. If we could go together, and the nurse could explain to him, then he would accept it easily.

30-year-old ‘near-miss’, *Paper II*

And one man similarly reflected: “When she comes home and tells you what they have told her, you just listen [to her] but do not care, because you were not there” (34-year-old, man, *Paper III*).

To be allowed inside the ward during labor was perceived as non-negotiable, and only possible at private facilities. Yet, only a few of the men had actively questioned why they were not allowed in and the cultural understanding of maternity wards as being solely a female domain was present in the narratives. Although men were not allowed in, they were still held to a principle of responsibility. One man had been asked to sign a consent form for caesarean section, and said:

They ask you to give your ID number and sign that you are there to make sure she is safe. But, then, after you sign, they turn around and lock you out of the delivery room. So, how am I supposed to ensure that my wife and kid are safe if am locked out of that room?

29-year-old, man, partner to ‘near-miss’, *Paper III*

Unpublished material: The women expressed varying opinions towards male involvement during childbirth. Most women argued that men were too “weak” to participate, and that it would not be appreciated by healthcare providers. However, a prominent reflection was that it would be good if a man could witness the pain a woman goes through during childbirth, and said: “If men would understand how much suffering we go through during childbirth, they would not hesitate to start using contraceptives” (Woman, FGD, *unpublished material*).

Discussion

The findings in this study identify a number of paradoxical barriers to maternal survival from the perspectives of women who nearly died due to a pregnancy-related complication (near-miss), their partners, community members, and healthcare providers working in abortion-related care in Kigali. The experience of these participants, representing the bottom-up perspective on policy implementation, will be discussed under three main headings: *Criminal label on early-pregnancy health needs; Imposed uptake of (suboptimal) maternal care; Men required yet dismissed in maternal care.*

Criminal Label on Early-pregnancy Health Needs

The women who wanted to have an abortion faced a lack of safe care options, which resulted in their resort to seek unsafe solutions, and subsequently contributed to the near-miss event. While it is known that legal restrictions will not hinder women from carrying out abortion, it is also highlighted as an inequity (19,41). It is probable that women in the urban setting, with contacts, a support network and the ability to pay, have the option to access relatively safe abortions (68). The amendments to the abortion law in 2012 made by Rwanda's top-level legislation and policymakers resulted in the condition that abortions are allowed under certain circumstances (rape, incest, forced marriage or threat to life) (74). However, the women in our study were not aware of these options, and it is likely that the information regarding the necessary circumstances to allow abortions have not reached the grassroots level. The healthcare providers expressed that nothing had changed in practice, partly due to the laborious court procedures involved in trying cases for legality. A recent newspaper article, published on 21 March, 2016 in Rwanda's leading English daily, *The New Times*, reports that the Rwanda Law Reform Commission has proposed that court procedures should be changed because today such a procedure may take up to a year and that, therefore, the "law isn't helping the people it was intended to protect" (156).

Rwanda is identified as being exceptional in its realization of the abortion law in the region. In one prison, 21 out of 114 women were imprisoned due to an illegal abortion, and 90% of them were 25 years old or younger (75). This was also reflected in our findings as one young woman had been reported to the police by her neighbor, who had assumed she had provoked the termination of her pregnancy. In line with this finding, a recent report claims that women who have had a spontaneous abortion have faced charges or imprisonment in Rwanda (157). Such a situation may pose an obstacle for

women seeking care, regardless of whether the abortion is provoked or spontaneous, as they may be at risk of being prosecuted.

In relation to the current abortion law, our findings highlight a paradox in the dual duties of healthcare providers. This corresponds with what Lipsky (2010) calls the ‘paradoxical reality’ of, on the one hand providing a service and, on the other hand, following laws and regulations. While most healthcare providers expressed their reliance on a professional code of ethics, assuring patient confidentiality, one healthcare provider pointed out that a supervisor had informed staff about the obligation to report known illegal abortion cases to the police. It has been revealed that a subset of women imprisoned for abortion in Rwanda were reported by healthcare providers after seeking help for their complications after undergoing an unsafe abortion (75,157). Also, from the healthcare providers’ perspective in our study, this was highlighted as a potential cause for delayed care-seeking among women. In addition, our findings indicate that healthcare providers may take precautionary measures so as to not face liability themselves. This was also seen in a recent study from Senegal, where healthcare providers obscured induced abortions in medical records so as to not later be held liable (88). This may also contribute to the underreporting of abortion-related maternal morbidity and mortality in Rwanda.

The availability of misoprostol is another aspect worthy of attention. The top-down intention of promoting the usage of misoprostol prior to other types of treatment is to expand access to post-abortion care, along with task-shifting this service to allow it to be offered at health center level. However, the bottom-up perspective of the interviewed healthcare providers in our study expressed a restricted availability of misoprostol and, thus, an inconsistency in the implementation of this policy. A recent study from neighboring Uganda demonstrates that midwives can provide it as successfully as physicians in post-abortion care, as well as the acceptability by women of using misoprostol (83,84). The restricted availability of misoprostol in Rwanda does not only have implications for abortion-related care, but may also have consequences for women in later stages of pregnancy as this is a cheap and effective measure for inducing labor and treating post-partum hemorrhage (158,159).

The recent amendment to the abortion law in Rwanda has been argued to be an important step as abortion has long since been a taboo topic (75). However, in settings where abortions have been legalized, such as Ethiopia and South Africa, and liberalized, such as Zambia, it has been demonstrated that women still undergo unsafe abortions, partly due to a lack of knowledge of the law, but also due to the stigma and fear of social sanctions (22,160,161). Stigma in relation to abortion is often upheld by the ideals of

femininity and womanhood, and rooted in discourses of morality (162,163). The consequences of abortion-related stigma were prominent in our findings. Apart from the threat of death due to hiding abortion-related symptoms out of fear of stigma, stigma also brings consequences beyond mere survival. We identified social sanctions associated with losing employment due to the suspicion of an illegal abortion. Furthermore, it has been reported that having an abortion or facing an unwanted pregnancy may cause girls to drop out of school, while boys can continue as usual (164,165). This imbalance in responsibility for abortions has also been pointed out by others, as a woman may often feel pushed, directly or indirectly, by her intimate partner to undergo an abortion (166). This gender imbalance is important to bear in mind in Rwanda's quest for gender equity. While healthcare providers can be seen as important implementers in tearing down abortion stigma, they expressed reluctance to further legalization of abortion, which was identified as partly being due to an unwillingness to have their profession associated with abortion. The stigmatization of abortion providers is a global phenomenon (167) and is an aspect of the professional role that requires mandated support.

Although contraception, in theory, is provided free of charge, or subsidized, cultural norms and ideals are found to pose hurdles to using contraception, particularly for young women (57,73). Our findings support that the women's need for contraception is unmet. Another study from Rwanda also shows that young women are denied access to contraception by the pharmacist or healthcare providers (164). Research from other studies in sub-Saharan Africa also reveal structural barriers to women's access to contraception, where adolescents in particular are a vulnerable group, and marital status is considered an important factor for eligibility (168).

The top-down approach with the recent amendment to the abortion law and the priority of reducing abortion-related deaths provides a momentum for change. Yet, from the bottom-up perspective, fear of litigation and stigma poses hurdles for women's care-seeking in early pregnancy and access to induced abortion in public maternal care is perceived as non-existent.

Imposed Uptake of (suboptimal) Maternal Care

Institutionalized maternal care, and particularly facility-based childbirth, was identified as mandatory by the women and men in this study. While most of the participants seemed to support the policy of facility-based childbirth, they questioned the system of fines if women were unable to reach the facility on time. The women's near-miss experiences shed light on a number of barriers to optimal care. Experiences of not being listened to, or not given

proper explanations by healthcare providers, were shared by the near-miss women, as well as their partners. A recent observational study from Rwanda validates our women's narratives, reporting that women were overlooked, shouted at, and being forced to give birth on their backs against their wishes (169). A further occurrence found in our study was that of women being held at the facility until they were able to pay for their treatment. All of these aspects can be identified as examples of 'disrespectful care', as conceptualized by others (170–173). Lack of respect in healthcare encounters has previously been reported in sub-Saharan Africa (169,174,175) and other contexts, such as India (176). Addressing the problem of disrespectful care is emphasized as an important interlinking factor in improving quality of care and maternal health (16,91,177).

The consequences of disrespect seem to have contributed to women's delayed care-seeking, expressed as a fear of coming 'too early' for antenatal care and childbirth. Disrespect in the care encounter may make women hesitant to raise concerns, which again can contribute to why symptoms, such as hypertensive disorders, go unnoticed. This was found in our study and is also identified in another study on near-miss from Kigali, where hypertensive disorders were a prominent factor related to morbidity and had not been detected during pregnancy (40). Another aspect of disrespect is that healthcare providers may withhold important information. Women in our study expressed having received inadequate information regarding certain symptoms to pay attention to, and factors associated with the near-miss. It has been identified elsewhere that women of lower socioeconomic and educational status may be treated as being unable to comprehend medical issues, and are therefore not provided adequate explanations by healthcare providers (178,179). In line with our findings, the need to strengthen communication, both between patient-provider and provider-provider, and between healthcare facilities, were noted as being important aspects in a recent report covering maternal death audits from Rwanda (67).

Parallel to this top-down goal of facility-based childbirths, the women described an uptake of traditional medicine. Traditional medicine was mostly sought as a preventive measure, or 'to get ready', for childbirth. This was a combination of a wish to protect oneself from 'witchcraft', and/or a wish to increase the intensity of contractions. The latter was also identified as a measure taken to enhance admission and care. Similar strategies taken have been identified in, for example, Burkina Faso prior to seeking care at a biomedical facility (180). Other identified factors for turning to traditional medicine in our study were to treat symptoms when public maternal care had not been of help. One supportive factor for this was that the traditional healer also offered other payment options than money, or the possibility to arrange a payment plan, also recognized as an incentive in other settings (181).

While the community-based health insurance scheme was identified as a supportive factor for care-seeking, costs were still a barrier. The payment system in place, requiring that most costs are covered prior to treatment, may delay the provision of care. On the other hand, the practice of fining women for not giving birth at a facility, while at the same time imposing sanctions such as women being ‘locked in’ if they are not able to pay for care, can also be identified as a paradox in the system.

While measures to limit the use of traditional medicine have been discussed at policy level (53), these traditional medicines, particularly those taken prior to childbirth, are assessed as potentially harmful for the woman and newborn (94,182). From the bottom-up perspective, a fine system was already in place at some health centers as a way to sanction women who had taken traditional medicine, which had made these women take them in secret instead, and brought about potential paradoxical consequences such as not allowing unsealed bottles to be distributed inside the health facilities. Other studies point out that the uptake of biomedical care in sub-Saharan Africa often continues in parallel with traditional medicine, and that increased uptake of public health care requires *trust* in the provided care (180,183). In our findings, *distrust* was present as women and men expressed a will to seek treatment at another facility the next time, to take actions outside of the public healthcare system, or they did not have faith in the advised treatment. However, the issue of trust and context-specific patient satisfaction warrants further exploration in this setting.

The top-down approach is to institutionalize public maternal health services, and particularly childbirth, with the aim of reducing the number of maternal deaths. The bottom-up perspective understands facility-based childbirth as being mandatory. However, our findings illuminate that disrespectful care and distrust in public healthcare services is prominent, which may lead to delayed care-seeking and suboptimal maternal health outcomes.

Men Required yet Dismissed in Maternal Care

The findings in this study highlight how the top-down initiative of increasing men’s involvement at the first antenatal care encounter has turned into a requirement with potential implications for women’s access to care. It was identified that women who arrived at the first antenatal care appointment alone were turned away and asked to return with their partner. This could lead to women attending antenatal care with a man who is not necessarily the partner – in order to access care. Obviously, this heightens the vulnerability of women who are pregnant outside of partnership and increases women’s dependency upon men, which subsequently reinforces normative relation-

ships. This is in contrast to Rwanda's agenda for gender equity. The consequences of women being denied access to care or put last in line in the implementation of male involvement for antenatal care has also been revealed in recent studies from Kenya and Malawi (179,184) and Tanzania (185).

Our findings suggest that the structural changes of involving men in antenatal care may have opened up an increased interest for men to take part in maternal care. A reason that men wanted to participate in antenatal care and childbirth appeared to be the wish to gain more insight into maternal issues and to ensure quality of care for their partner. Other studies in sub-Saharan settings, however, pointed out that men were reluctant to join their partner due to disrespectful healthcare providers (112,186). It may be that the reflections of the men in our study were formed by the experience of their partners' near-miss, similar to findings from Uganda (110), and that they therefore express an increased wish to participate in maternal care. However, the men's expressed interest in participating in their partners' antenatal care may also be due to participation being enforced.

While the men were interested in taking part in pregnancy-related information and care, they perceived that healthcare providers excluded them from this. Similar perceptions have been identified in another study from Rwanda (113). This could be seen as a persisting norm to uphold maternal care as a female domain. Limited access and insight may provoke men's distrust in the public health system and healthcare providers. Also, some of the women expressed a wish to involve their partners in pregnancy-related care. For male involvement to serve its purpose of improving maternal health outcomes and gender equity, the initial aim should be revisited and clarified at both policy and health system level, but also at grassroots level. Other studies have highlighted the positive aspects of male involvement in promoting gender equity (119,187). The high number of men attending antenatal care in Rwanda provides an opportunity to increase men's awareness about maternal health, however, if the aim is to also promote gender equity, persisting societal gender norms need to be addressed.

From the top-down perspective, encouraging male involvement in reproductive health matters is one of the approaches to increase gender equity, and the specific action point has been to involve the male partner at the first antenatal care visit. In contrast, from the bottom-up perspective, men's attendance is perceived as being a mandatory for a woman to access antenatal care; yet, at the same time, men's increased interest in involvement is experienced, by themselves, as being dismissed.

Strengths and Limitations

This thesis is built on qualitative research guided by the framework of naturalistic inquiry. To ensure trustworthiness, a thick description of the research process, and reflections on methodological and ethical dilemmas, are provided in the methods sections. This chapter provides final reflections.

The strength in this thesis is that multiple perspectives on the studied phenomenon have been captured, which include the voices of men, women, and healthcare providers. The interviews took place in various settings, and some participants were met many times, something that enhanced the depth and nuances of their perceptions and experiences. Another strength was that the interpreter was very involved in the research process, could guide me in the cultural setting and provided an opportunity to discuss and reflect on important aspects emerging in the interviews and observations. The insider-outsider debate in conducting cross-cultural research is much discussed. An advantage of being an outsider, as I am to the Rwandan context, could be to observe aspects taken for granted by insiders of the same culture.

On the other hand, being a cultural outsider, not knowing the language and being dependent on an interpreter obviously posed some limitations to gaining a full understanding of the complexity of the Rwandan context. Due to the limited scope of this thesis, there were aspects that emerged, but that have not been analyzed to the depth that they might deserve. This includes certain aspects of cultural understandings and religious beliefs, as the focus was primarily set on barriers to care. While community health workers are considered important in the Rwandan health system, I did not include these in my study as I wanted to limit the scope. However, including the voices of community health workers could be an additional perspective to bring forward in future studies. Another potential limitation in this work is that gender-based violence was not further explored. Including this aspect may have provided a different angle on male involvement, and is an important aspect that should be examined in more depth. Reflecting back on the data collected with healthcare providers, another aspect left out was whether the ‘payment-for-performance’ scheme influenced their work in abortion care. This is also an important element for future research.

Conclusion

This thesis highlights paradoxical outcomes in the implementation of maternal care policies in Rwanda. Despite amendments of the abortion law in 2012, safe abortion within the public health system was identified as non-accessible in practice. Abortions are stigmatized and have a criminalized label, which not only creates risk-taking and clandestine solutions to unwanted pregnancies, but also creates care-seeking delays, and social sanctions for women who experience obstetric complications in early pregnancy. Fear of litigation was identified among healthcare providers, potentially placing hurdles to the optimal provision of abortion counseling and care.

Giving birth at a health facility was perceived as mandatory, yet the counseling and care provided there was identified by women and their partners as disrespectful and suboptimal. This did not only contribute to inadequate or inappropriate treatment, pushing women to seek care repeatedly, but also to generating distrust in public healthcare – interpreted as reinforcing the parallel adherence to traditional medicine.

In contrast to the increased number of men attending antenatal care, this thesis reveals a perceived obligation to be accompanied by a man in order to receive care. This requirement not only poses discrimination toward single women or to women coming alone, but may push women to come with a random man, who is neither the intimate partner nor the father of the coming baby, in order to receive care. This places women in a dependent situation on men in their care-seeking – which is contrary to Rwanda’s agenda of empowering women. Paradoxically, while the top-down agenda of improving the engagement of men in reproductive health matters seeks to increase gender equity, this thesis identifies that men perceive themselves as being excluded and dismissed in maternal care. The current maternal health system is thus missing the opportunity to embrace men’s interest to take part in childbearing, which may also provoke distrust in the available care.

To better ensure that health care corresponds with the agenda for maternal survival, the findings of this thesis give reason to pause and consider the perspectives of those being asked to practice them and to continue to strengthen the maternal health system to avoid contradictory results.

Recommendations

The findings in this thesis identify unintended and contradictory consequences of Rwanda's well-intended maternal health policy. The following recommendations can be suggested:

Abortion care

- Strengthen the procedure to access a legal abortion, and address the highlighted gaps in the current implementation
- Develop clearer guidelines to protect the confidentiality of each patient, particularly in regards to whether a healthcare provider should, or should not, report a woman who discloses an illegal abortion
- Strengthen healthcare provider awareness about the amended abortion law and improve training for abortion care procedures

Antenatal care and male involvement

- Develop policy to better accommodate men's inclusion in maternal health matters
- Increase flexibility in the antenatal care recommendations to encourage women to attend antenatal care with or without their partner, or with someone of their choice

Facility-based childbirth

- Revisit the potential for increased flexibility of paying for healthcare, such as payment in installments, and reconsider subsidization of certain medicines
- Ensure the provision of respectful antenatal, childbirth and post-partum care, and improve means of communication about symptoms of potential complications requiring attention

Summary in English

Rwanda is currently undergoing rapid changes to reach the ambitious goal of achieving improved health and wealth by the year 2020. Within this goal, maternal survival and gender equality are among the main priorities. The country has made remarkable progress in rebuilding its health system after the genocide of 1994 and has demonstrated substantial advancements in its work to improve maternal health. Rwanda was one of the few countries to have reached the Millennium Development Goal of decreased maternal deaths by 2015. Maternal mortalities have decreased substantially and, today, nearly all women give birth at a health facility. Rwanda has also put a community-based health insurance scheme in place, and is working in the direction of providing universal health coverage. Increased attention is also being placed on reducing population growth by improving reproductive health and increasing the use of contraceptives. One important step taken was the amendment of the abortion law in 2012, opening up opportunities for women to seek a legal abortion if the pregnancy was a result of rape, incest or forced marriage, or if the pregnancy is a threat to the life of the woman.

This thesis builds on qualitative research with women who nearly died, but survived, as a result of a severe obstetric complication during pregnancy; their partners and other recent fathers; healthcare providers working within the public health system; and community members, most living within the suburbs of Kigali. The aim of this study is to lift their perspectives and experiences of maternal care, and to identify potential barriers to Rwanda's policy agenda for improved maternal health. Data were collected between 2013 and 2016.

The findings highlight current paradoxes in the quest to improve maternal health in Rwanda. Despite the amendments to the abortion law, our findings suggest that not much has changed in practice. Safe abortion seems to be inaccessible within the public health system, and abortions carry a criminal and stigmatized label. This does not only cause risk-taking and clandestine solutions to unwanted pregnancies, but also care-seeking delays, discrimination and social consequences for women with complications requiring care in early pregnancy. Post-abortion care is available, but, due to the fear of criminalization or social sanctions, women show hesitancy in

seeking this care. Here, married women seem to be protected from suspicion from the community, but not necessarily from their intimate partner. This thesis also brings to light the healthcare providers' perspective on the amended law and the provision of abortion care, and reveals that not all of them were correctly informed, or supportive, of the amendments. The findings unveil tensions in the duty of being a care provider while also a law enforcer, and the uncertainties about care-professionals' rights and responsibilities if an illegal abortion is disclosed in the care encounter. This has also been interpreted as a reason why women delay seeking care, as their confidentiality may not be ensured.

Antenatal care, consisting of four visits and initiated early in pregnancy, is promoted to monitor pregnancies and provide health education. Within the provision of antenatal care, HIV testing is an essential part of the work to prevent maternal-to-child transmission where the woman is HIV positive. Within this strategy, Rwanda is encouraging partner testing for HIV. From the perspective of our findings, this well-intended initiative of male attendance at the first visit seems to have turned into a requirement in order to receive care. This counterproductively caused delays or excluded women who came alone. However, supportive men were seemingly turned away from further health consultations. This was identified as a missed opportunity to provide health education to the expectant couple, and to promote gender-equitable attitudes in favor of women's health during pregnancy and childbirth.

It was perceived as mandatory to give birth at a health facility. The government has implemented this as a strategy to increase the rate of childbirth by skilled personnel. This perceived 'rule' was adhered to in order to avoid being fined if giving birth at home. Facilitating factors for seeking care on time included having insurance coverage and if there was someone available to accompany the woman. However, the insurance did not cover all medicine, and some participants still faced challenges in meeting the costs. Here, healthcare providers sometimes contributed to the shortfall from their own pockets. This thesis also highlights structural barriers such as long waiting times, delays in admission, constraints in referrals, or not being able to leave the hospital until the hospital bill was paid.

Despite the imposed uptake of antenatal care and facility-based childbirth, the quality of care was experienced as inadequate. Participants in this study had experiences of disrespect in the care encounter in the form of being overlooked by healthcare providers, not listened to, or not being given proper explanations. This contributed to women's reluctance to raise concerns, early signs of complications being left unnoticed during antenatal care, and inadequate or inappropriate treatment post-abortion or post-partum

– pushing some women to seek care – again. These experiences were found to trigger distrust in public maternal care, and made some women seek solutions from traditional medicine instead.

Parallel to seeking care at public health facilities, adherence to traditional medicine seems to be persisting during pregnancy, and particularly right before childbirth. Traditional medicine was taken as a preventive measure for the protection from potential witchcraft or to facilitate childbirth, particularly by increasing contractions. This seems to be rooted both in a socio-cultural interpretation of causes of disease, but also in a distrust of public maternal care, triggered by experiences, or anecdotes, of disrespectful encounters. Other reasons for a preference to seek care by a traditional healer seemed to be the option to delay payment, or to pay in installments, a possibility not offered in the public health facilities included in this study. Rwanda wishes to control the usage of traditional medicine, and the participants in this thesis described incidents where health facilities imposed fines, or threatened to do so if traditional medical advice was sought. Therefore, traditional medicine was often taken in secrecy.

Improved engagement of men in reproductive health matters is recognized as an important element in improving maternal health. The men in this thesis expressed wishes to carry responsibilities during childbearing beyond their ‘traditional roles’ of being the financial provider. They also demonstrated willingness to negotiate their involvement according to their partners’ wishes, external expectations, and perceived cultural norms. However, the men perceived the maternal health system, care providers, and policies, as being resistant toward their increased engagement in childbearing.

In conclusion, this thesis points at certain aspects worthy of attention to align with the agenda for improved maternal health in Rwanda. Enhanced implementation and increased awareness of the amended abortion law is recommended. To not discourage women without a partner from attending antenatal care, improved flexibility is needed. Increased inclusion of men during pregnancy and childbirth is suggested, however, not at the expense of women’s empowerment. The strengthening of the quality and continuum of care is vital, paying particular attention to assuring respectful interaction with patients and providing clear and understandable information to both the women and their partners.

Summary in Kinyarwanda – Incamake

Muri iki gihe u Rwanda ruri kugira impinduka zihuse zigamije ku kugera ku ntego yo guharanira ko abaturage barushaho kugira ubuzima bwiza kandi n'ubukungu bukiyongera mu mwaka w'i 2020. Ni muri urwo rwego, kurengera ubuzima bw'ababyeyi ndetse n'uburinganire bw'ibitsina ari ingingo zitabwaho by'umwihariko. U Rwanda rwageze ku ntambwe ishimishije mu kongera kubaka urwego rw'ubuzima nyuma ya jenocide yabaye mu mwaka w'i 1994, kandi rwagaragaje ibikorwa byinshi rwagezeho mu bijyanye no guteza imbere ubuzima bw'ababyeyi. U Rwanda ni kimwe mu bihugu bike byageze ku ntego y'ikinyagihumbi (Millennium Development Goal) yo kugabanya impfu z'ababyeyi mu mwaka w'i 2015. Impfu z'ababyeyi zaragabanutse cyane, kandi muri iki gihe, hafi y'abagore bose babyarira kwa muganga. U Rwanda kandi rwafashije abaturage kubona ubwisungane mu kwivuza kandi rurimo guharanira ko abantu bose babasha kubona ubuvuzi bw'ibanze biboroheye. Ingufu nyinshi kandi zirimo gushyirwa mu kugabanya umuvuduko w'ubwiyongere bw'abaturage biciye mu kwita ku buzima bw'imyorokere ndetse no kurushaho gukoresha uburyo bwo kuboneza urubyaro. Intambwe imwe ikomeye yatewe ni iyo guhindura itegeko rirebana no gukuramo inda mu mwaka w'i 2012, bityo bigaha uburenganzira abaganga bwo kuba bakuriramo inda abagore bafashwe ku ngufu, abatewe inda n'abo bafitanye isano rya hafi cyangwa abashyngiwe ku gahato, cyangwa se abagore bashobora kugira ingaruka zikomeye harimo n'urupfu bikomotse ku gutwita.

Iki gitabo gikubiyemo ubushakashatsi bwakorewe ku bagore bari bagiye guhitanywa n'inda ariko bakarokoka nyuma yo kurwara bikomeye biturutse ku gutwita, abagabo babyaranye n'abo bagore ndetse n'abandi bagabo bari baherutse kubyara vuba, abaganga n'abandi bavuzi bakorera mu mavuriro ya Leta, ndetse n'abandi baturage, bose batuye mu muji wa Kigali. icyari kigamijwe n'ubu bushakashatsi kwari ugukusanya ibitekerezo byabo ndetse n'ubuhama bwabo ku bijyanye n'ubuvuzi buhabwa ababyeyi, ndetse no kureba inzitizi zishobora kubangamira u Rwanda mu kugera ku ntego yo kurushaho kubungabunga ubuzima bw'ababyeyi. Ubu bushakashatsi bwakozwe hagati y'umwaka w'i 2013 na 2016.

Ibyavuye muri ubu bushakashatsi bigaragaza ibirimo kuba muri iki gihe u Rwanda rurimo guharanira kubungabunga ubuzima bw'ababyeyi kurushaho.

Nubwo hari ibyahinduwe mu itegeko rigena gukuramo inda, ibyo twakuye mu bushakashatsi bwacu bigaragaza ko mu bikorwa nta kintu kinini cyahindutse. Gukuramo inda mu buryo bwizewe ntibishobora gukorwa mu mavuriro ya Leta, kandi gukuramo inda bifatwa nk'igisebo kandi bigahanirwa n'amategeko. Ibi rero bituma abagore batwaye inda batabishaka bazikuramo rwihishwa batitaye ku ngaruka byabatera, kandi bagatinda kujya kwa muganga, tutibagiwe n'akato n'izindi ngorane bahura na zo mu gihe baba bakeneye ubuvuzi nyuma yo gukuramo inda mu mezi abanza yo gutwita. Ubuvuzi ku bagore baba bakuyemo inda burahari, ariko kubera gutinya gukurikiranwa n'inzego z'ubutabera cyangwa guhabwa akato, abenshi batinya kujya kwa muganga. Nubwo abagore bashakanye n'abagabo babo byemewe n'amategeko bakunze kudakekwaho gukuramo inda, uru rwikekwe rushobora kutabuta hagati yabo n'abo bashakanye. Ubushakashatsi twakoze bwagaragaje kandi imyumvire y'abatanga ubuvuzi ku byahinduwe mu itegeko rigenga gukuramo inda, bwerekana ko atari bose barisobanukiwe neza cyangwa bashyigikiye impinduka zarikozweho. Ivyavuye muri ubu bushakashatsi bigaragaza ikibazo giterwa no kuba ari wowe utanga ubufasha mu buvuzi, akaba ari nawe ureba ko abarwayi bakurikiza amategeko, kuba abakora mu nzego z'ubuzima batazi neza uburenganzira n'inshingano zabo mu gihe bagomba kugaragaza ko inda yavuyemo mu buryo butemewe n'amategeko mu gihe barimo kuvura uwayikuyemo. Ibi rero bikaba byarafashwe nk'imwe mu mpamvu zituma abagore batinda kujya gusaba ubufasha kwa muganga, kuko baba batizeye ko ibyo babwira muganga atazabizimura.

Kwisuzumisha inshuro enye kandi bigatangira mu mezi ya mbere yo gutwita ni ikintu ababyeyi bashishikarizwa cyane mu rwego rwo gukurikiranira hafi inda batwite no kubaha ubumenyi ku bijyanye n'ubuzima. Muri uko kwisuzumisha ku bagore batwite, harimo gusuzumwa agakoko gatera SIDA, bikaba ari igikorwa cy'ingenzi gituma hirindwa ko umubyeyi yanduza umwana mu gihe basanze umubyeyi yanduye. Ni muri urwo rwego, guverinoma y'u Rwanda ishishikariza abagabo kujyana n'abagore babo kwipimisha. Dukurikije ibyo twabonye mu bushakashatsi bwacu, iyi gahunda nziza yo gushishikariza abagabo guherekeza abagore babo mu gihe bagiye kwipimisha inda ku nshuro ya mbere, yahindutse nk'itegeko ngenderwaho kugira ngo umugore yakirwe kwa muganga. Ibi rero byatumye abagore batazanye n'abagabo batinda kwisuzumisha cyangwa bagasubizwa inyuma. Hagati aho kandi, abagabo babyifuzaga nabo babujijwe kugaruka ku zindi nshuro umugore agarutse kwisuzumisha. Iki ni ikintu dushaka kugaragaza nk'uburyo butakoreshejwe neza kandi bwari gufasha umugore n'umugabo kwigishwa ku bijyanye n'uko bakwifata mu gihe cyo gutwita, bakarangwa n'ibikorwa by'ubwuzuzanye hagamijwe gufasha umugore mu gihe cyo gutwita ndetse n'icyo kubyara.

Twasanze kubyarira kwa muganga bifatwa nk'itegeko. Guverinoma yakoresheje ubu buryo mu rwego rwo kongera umubare w'ababyeyi babyarira kwa muganga babyajwe n'abakozi babyigiye. Aya mabwiriza akaba akurikizwa mu rwego rwo kwirinda gucibwa amande ku babyariye mu rugo. Ibyorohereza abantu kujya kwa muganga twasanze harimo kugira ubwisungane mu kwivuzza ndetse no kugira umurwaza uherekeza umubyeyi. Hagati aho, ubwisungane mu buvuzi ntabwo bwishyura imiti yose, bityo bamwe mu barwayi bakabura ubushobozi bwo kugura imiti imwe n'imwe. Ibi bigatuma habaho igihe abavura bishyurira abarwayi bakoresheje amafaranga yabo bwite. Ubu bushakashatsi kandi bwagaragaje inzitizi zirimo gutegereza umwanya munini mbere yo kubonana na muganga, gutinda gushyirwa mu bitaro, gutinda koherezwa ku yandi mavuriro, no kwanga kurekura umurwayi ngo asohoke mu bitaro mu gihe atarishyura umwenda wose abereyemo ibitaro.

N'ubwo ababyeyi bategekwa kwisuzumisha hakiri kare mu gihe batwite ndetse no kubyarira kwa muganga, ubufasha butangwa kwa muganga twabwiwe ko budahagije. Hari abo twaganiriye muri ubu bushakashatsi batubwira ko bahuye n'ikibazo cyo gusuzugurwa, ibi bakaba barabishingiye kuko ababaga babavura batabitayeho bikwiye, ntibabatege amatwi bihagije cyangwa se ngo babahe ibisobanuro bihagije. Ibi rero bikaba byaratumye abagore batinya kugira icyo babaza, hanyuma ibimenyetso bimwe bigaragaza uburwayi ntibyitabweho mu gihe umugore utwite aje kwisuzumisha, ndetse no kuvurwa nabi cyangwa bidahagije nyuma yo gukuramo inda cyangwa kubyara – ibyo bigatuma abagore bamwe basubira kwa muganga kuko baba batavuye neza. Ibi rero byagiye bituma hari abantu bata icyizere bari bafitiye abaganga bita ku babyeyi, ndetse bigatuma abagore bamwe baja gushaka ubufasha mu bavuzi ba gakondo.

Kujya kwa muganga ababyeyi benshi bakunze kubibangikanya no kujya kureba abavuzi ba gakondo mu gihe batwite ariko cyane cyane mbere yo kubyara. Imiti ya kinyarwanda ifatwa akenshi nk'uburyo bwo kurinda ababyeyi kuba barogwa kandi igafatwa nk'ishobora korohereza umubyeyi kubyara imwongerera ibise. Ibi bikaba bishamikiye kubyo umuco wa kinyarwanda ufata nk'intandaro y'uburwayi ku mubyeyi ndetse no kuba ababyeyi bamwe batizera ubuvuzi bwo mu mavuriro amwe namwe bashingiye ku biba byarababayeho, ndetse n'inkuru babwirwa n'abandi zijyane no gusuzugurwa. Izindi mpamvu zituma ababyeyi bamwe bagana abavuzi ba gakondo harimo no kuba bashobora guhabwa n'aba bavuzi ideni cyangwa bakabemerera kwishyura buhoro buhoro, ibi bikabwa bidashoboka mu mavuriro ya Leta harimo nayo twakoreyemo ubushakashatsi. U Rwanda rurashaka gukurikirana imikoreshereze y'imiti gakondo, ndetse bamwe mu bakoreweho ubushakashatsi bavuze ko bigeze gucibwa amande kubera gukoresha iyo miti, cyangwa bakabwirwa ko bazayabaca nibajya kwivuzza ku

bavuzi ba gakondo. Ibyo rero bikaba byaratumye bajya kureba abo bavuzi ba gakondo rwihishwa.

Kuba abagabo bararushijeho kwitabira gahunda z'ubuzima bw'imyororokere ni intambwe ikomeye yatewe mu kubungabunga ubuzima bw'umubyeyi. Abagabo twaganiriye muri ubu bushakashatsi bagaragaje ko bifuzwa kugira uruhare rugaragara mu gufasha abagore babo mu gihe batwite, ntibikomeze gufatwa ko umugabo ari uwo guhahira urugo gusa nkuko bimenyerewe mu mucu wa kinyarwanda. Bagaragaje kandi ubushake bwo kuganira ku ruhare rwabo mu gufasha abagore babo hagendewe ku byifuzo bafite, ibyo bifuzwa gukorerwa n'abandi, n'ibyo umuco w'igihugu uteganya. Gusa muri ubu bushakashatsi abagabo bavuze ko inzego zishinzwe ubuzima bw'ababyeyi, abaganga bazikoramo, ndetse n'amategeko agenderwaho, bitorohereza kuba bagira uruhare rwisumbuyeho mu gufasha abagore babo mu gihe batwite.

Muri make, ubu bushakashatsi bugaragaza ingingo zimwe na zimwe zikwiye kwitabwaho mu rwego rwo kugendera mu murongo u Rwanda rwifuzwa wo kubungabunga ubuzima bw'umubyeyi kurushaho. Kurushaho gushyira mu bikorwa no kumenyekanisha ibyahinduwe mu itegeko rigenga gukuramo inda ni ikintu tubona ko ari ingenzi. Kutabuza kwisuzumisha abagore baje kwa muganga batazanye n'abagabo babo, ahubwo hakitabwaho kumva impamvu zabo birakenewe. Kongera uruhare rw'abagabo mu gufasha abagore babo mu gihe batwite cyangwa babyara ni igitekerezo cyiza, ariko ibyo bigakorwa hatabangamiwe uburenganzira bw'umugore. Kurushaho kunoza ubuvuzi buhabwa ababyeyi ni ikintu cy'ingenzi, cyane cyane hitabwaho ku kwakirana icyubahiro abarwayi baje kwivuzwa no gusobanurira bihagije abagore n'abafasha babo baje kwa muganga.

Sammanfattning på svenska

Rwanda genomgår för närvarande snabba förändringar för att nå det ambitiösa målet om förbättrad hälsa och välbefinnande till år 2020. Huvudprioriteringar för att nå detta mål är att öka överlevnaden för mödrar samt förbättra jämställdheten mellan kvinnor och män. Efter folkmordet år 1994 har Rwanda gjort anmärkningsvärda framsteg i återuppbyggnaden av sitt hälso- och sjukvårdssystem samt i arbetet med att förbättra mödrahälsan. Rwanda var ett av få länder som år 2015 lyckades nå millenniemålet om minskad mödradödlighet. Antalet kvinnor som avlider i samband med sin graviditet har minskat kraftigt och idag föder nästintill alla kvinnor barn på en vårdinrättning. Rwanda har även infört en allmän sjukförsäkring och arbetar mot målet att alla individer ska täckas av försäkringen. Fokus har även lagts på att minska befolkningstillväxten, genom att förbättra den reproduktiva hälsan och öka användningen av preventivmedel. Under 2012 förändrades abortlagen i Rwanda, ett viktigt steg mot förbättrad reproduktiv hälsa, vilket öppnade upp för möjligheten till abort för kvinnor som blivit utsatta för våldtäkt, incest eller tvångsäktenskap, samt för kvinnor vars graviditet är livshotande.

Denna avhandling baseras på kvalitativ forskning med kvinnor som varit nära att mista livet på grund av svåra förlossningskomplikationer; deras partners och andra nyblivna fäder; och vårdgivare som arbetar inom det offentliga hälso- och sjukvårdssystemet, de flesta boende i förorter till Rwandas huvudstad Kigali. Syftet med avhandlingen är att belysa deras perspektiv och erfarenheter av mödrahälsovård och att identifiera potentiella hinder för Rwandas politiska mål för förbättrad mödrahälsa. Data samlades in mellan åren 2013 och 2016.

Resultatet av studien åskådliggör paradoxer i Rwandas strävan efter förbättrad mödrahälsa. Trots förändringar i abortlagen visar resultaten inte på några tydliga förändringar i praktiken. Säkra aborter verkar vara svårtillgängliga i det offentliga hälso- och sjukvårdssystemet och kvinnor stigmatiseras på grund av att aborter fortfarande anses vara en kriminell handling. Detta medför inte bara riskfyllda lösningar på oönskade graviditeter, utan även att vård inte söks i tid samt diskriminering av och sociala konsekvenser för kvinnor som drabbas av tidiga graviditetskomplikationer. Eftervård i samband med abort är tillgänglig men på grund

av rädsla för rättsliga eller sociala sanktioner är vissa kvinnor tveksamma till att söka vård. Samhället riktat sällan misstankar om abort mot gifta kvinnor, men dessa kan däremot mötas av misstankar från sina partners. Denna avhandling behandlar även vårdgivares syn på lagändringen samt på tillhandahållandet av abortvård. Resultaten visar att alla inte är informerade om, eller stöder, lagändringarna och att det finns en konflikt mellan en vårdgivares plikter och upprätthållandet av lagen. Vårdgivarna uttrycker även en osäkerhet kring sina rättigheter och skyldigheter att rapportera en kvinna om en illegal abort avslöjas i vårdmötet. Detta kan även vara en orsak till att kvinnor inte söker vård eftersom deras anonymitet inte kan garanteras.

För att övervaka graviditeten, och samtidigt tillhandahålla hälsoutbildning, förespråkas fyra mödrahälsovårdsbesök, med det första i tidig graviditet. En viktig del är HIV-testning för att förebygga överföring av HIV-smitta mellan moder och barn när modern är HIV-positiv. Inom ramen för detta arbete förespråkar Rwanda att även kvinnans partner testas för HIV. Resultaten i denna avhandling visar dock att ett välment initiativ för att få männen att närvara vid kvinnans första mödrahälsovårdsbesök istället upplevs som ett krav för fortsatt mödrahälsovård. Detta orsakade att kvinnor sökte vård senare i graviditeten eller blev nekade vård om de kom ensamma. Män som var stöttande under graviditeten upplevde att de blev exkluderade från att närvara vid själva hälsokonsultationen, samt vid vidare hälsokonsultationer. Detta identifieras som ett missat tillfälle att ge hälsouppllysning till de blivande föräldrarna, och att förespråka jämställdhet mellan föräldrarna till förmån för kvinnors hälsa under graviditet och förlossning.

Avhandlingen visar att det uppfattas som obligatoriskt att föda barn på en vårdinrättning. Regeringen har implementerat detta som en strategi för att öka antalet förlossningar assisterade av utbildad personal. För att undvika böter följdes denna ”regel” och man undvek därför att föda barn i hemmet. Faktorer som främjade att man sökte vård i tid var innehavande av ett försäkringsskydd och att kvinnan hade någon som kunde följa med henne till vårdinrättningen. Försäkringen täcker dock inte kostnaden för alla läkemedel, och vissa av deltagarna hade svårigheter att betala för vårdkostnaderna. I dessa fall hjälpte vårdgivarna ibland till genom att själva betala för läkemedlen. Denna avhandling pekar också på strukturella problem inom vården i form av långa väntetider, förseningar vid patientinläggning, begränsningar i remissutförande och krav på betalning av sjukhusräkningen för att få lämna sjukhuset.

Trots att mödrahälsovård och förlossning på sjukhus förespråkas, upplevdes vårdkvaliteten som otillräcklig. Deltagarna i denna studie hade erfarenheter av respektlöst bemötande från vårdpersonalen. Respektlösheten tog sig uttryck i förbiseende vårdgivare, att inte bli lyssnad på eller att inte få

ordentliga förklaringar. Detta bidrog till kvinnors ovilja att ta upp orosmoment, att tidiga tecken på komplikationer inte uppmärksammades samt till en otillräcklig eller olämplig eftervård efter abort eller förlossning, vilket i sin tur gjorde att vissa kvinnor blev tvungna att söka vård på nytt. Dessa erfarenheter skapade en misstro mot den offentliga mödrahälsovården, vilket ledde till att vissa sökte sig till och använde sig av traditionell medicin istället.

Parallellt med att söka vård på offentliga vårdinrättningar, söker kvinnor sig under sin graviditet, och framför allt i slutet av graviditeten, till den traditionella medicinen. Traditionell medicin ses som en förebyggande åtgärd för att skydda sig mot häxkraft eller för att underlätta förlossningen genom att framför allt öka antalet sammandragningar. Detta verkar vara förankrat både i en sociokulturell tolkning av sjukdomsorsaker, men även i en misstro mot den offentliga mödrahälsovården, utlöst av egna erfarenheter, eller andras anekdoter, om bristande respekt i vårdmötet. Andra skäl till att söka sig till den traditionella medicinen verkar vara en möjlighet att fördröja eller dela upp betalningen, en möjlighet som inte erbjuds av de offentliga vårdinrättningarna inkluderade i denna studie. Rwanda önskar kontrollera användningen av traditionell medicin, och deltagarna i denna avhandling pekade på att vårdinrättningar ålägger patienter böter, eller hotar med att göra det, om traditionell medicin används. Därför är användandet av traditionell medicin något som till stor del görs i hemlighet.

Ökat engagemang av män i reproduktiva hälsofrågor identifieras som en viktig del i att förbättra mödrars hälsa. Männerna i denna avhandling uttryckte att de utöver deras traditionella roll som "försörjare" även önskade bli involverade och ta större ansvar under själva graviditeten. De visade även på en vilja att anpassa sin involvering utifrån flera aspekter såsom sina partners önskemål, externa förväntningar och upplevda kulturella normer. Männerna upplevde dock att deras ökade engagemang under graviditeten möttes av motstånd från mödravården, vårdgivare, och befintliga riktlinjer.

Denna avhandling identifierar ett antal aspekter värda att prioritera för att komma framåt i arbetet med en förbättrad mödrahälsa i Rwanda. Förbättrad implementering av den nyligen ändrade abortlagen är önskvärd. För att inte avskräcka kvinnor utan en partner från att söka vård krävs större flexibilitet inom mödrahälsovården. Förbättrad inkludering av män under graviditet och förlossning rekommenderas, så länge det inte sker på bekostnad av kvinnors egenmakt. Förbättrad kvalitet och ett stärkt arbete med uppföljning av given vård är avgörande. Särskild fokus bör ligga på att säkerställa en respektfull interaktion mellan patienter och personal, samt att tillhandahålla tydlig information om vilka symptom både kvinnan och hennes partner bör uppmärksamma efter en behandling.

Acknowledgments

First and foremost, this project has not been possible without **ALL** of the women, men and healthcare providers who gave their time and generously shared their stories, as well as opened the doors to their homes – thank you each and every one!

To my supervisors who have pushed me in the right direction: Birgitta, your creative mind, your humor and your enthusiasm have made me go forward. Thank you for all the meetings that left me inspired!

Pauline, your insightful comments and incredible talent in conceptualizing have been so inspiring to me. Thank you for joining me in Rwanda, for the encouraging texts around the clock, for those early mornings in the U.S. (with decaf coffee...) and for so much more.

Marie, your sharp input, encouragement and caring words have always arrived when most needed. Thank you for being there.

I am also deeply grateful for all the support from the two Rwandan co-authors who have been included from the start:

Aimable, how can I thank you enough? Your support throughout these years has been invaluable. Stephen, thank you for your valuable insights and assistance in this project.

To Smålands Nation, Familjeplaneringsfonden and SIDA for the grants allowing me to realize this work.

To the Swedish Research Group for Global Health for the opportunity to take part in interesting seminars; To Bergmans Stiftelse for allowing me to spend a wonderful week on Fårö with peaceful writing and sheep around; to the U4 Summer School for a week full of gender discussions.

To my endlessly important colleagues and dear friends in Rwanda:

I am forever grateful that I have had this chance to get to know all of the warmhearted people who crossed my path.

I would like to express my sincere gratitude to the group of midwifery students who welcomed me to take part in their internship.

I am also heavily indebted to all the support I was given in finding clarity in this process:

Simba, for all the discussions at IRL and online throughout these years. You are such an inspiration to me. Thank you for being my friend!

Theo, for all the help during my fieldwork, and for your friendship, your support has been extraordinary!

Cassien, for your reflections and encouragement, I am grateful we finally got in touch.

Peter, you wise guy, for all the inspirational conversations and for your passion for midwifery.

April, for your generosity during my fieldwork – kiitoksia!

Karen, for those few meetings, but yet so appreciated.

Jovia, for all your important contributions in this process.

Tim, for your professionalism and efficiency as a translator. You impress me!

To my brother, Claude, for always making sure I reached my destination on time, and for cheering me up while getting there.

To my sister, Nicole, for your excellency as an interpreter, for your critical mind and for your warm heart.

To my Rwandan friends who welcomed me to their home:

Kristina and Lionel – thank you for opening your door and letting me stay with you. I am forever grateful for that and for your friendship, which I value deeply!

To Isabelle, Patrick and Nwari for doing the same! Thank you!
A special thanks to Isabelle for the tasty, and tasteful, dinners and deep kitchen-discussions, which I will carry with me forever.

To Elsie and family, for your warmhearted hospitality, and for the important work you do for women in Kigali.

To Moses and Emilienne and family, I care about you deeply, thank you for everything.

To Nathalie, for showing me a deeper understanding of life.

To Katie, for being such an inspiration and for making change happen.

To Laura and Ineke, for *all* those nice long chats throughout these years.

To Benjamin, Jennifer, and, Natalia for your input in my work and for the much appreciated lunches.

To Martina – or should I say *Marita*; for joining me in Kigali and all the memories we shared, and to Ibyishimo.

And to all of you, you know who you are, for all the dinners and runs.

To my dear colleagues and support in the North:

To all of my dear PhD colleagues at IMCH, past and present, thank you for everything, for inspiring me, and for making my time in Uppsala so great.

Special thanks to: Anna A for the trip to Brighton and for being my stand-in therapist; Anna B for most things unrelated to science, but still so important; Anna W, my roomie, for the pepp-wall, for the translation and for your friendship; Annika for being so kind and allowing us to work from your home; Elin T, my silver master – let's not forget about our plan B; Elin L, I hope there will be more runs on hilly roads somewhere far away; Emily, for your happy laughs and help outs!; Helena, for the lunches that have been and the lunches to come; Jill, not only for the sharp and insightful scientific comments, but also for opening my eyes to creative alternatives – you are a great source of inspiration to me!; Jonna, for your impressive observations and our walk-chats, tusen tack!; Mandira, my dear friend and 'partner in crime', for the car-tour in L.A. and all the rest – I hope we will work together again!; Maja for making things happen, and for making me believe in change; Maria, for your warm hugs; Paridhi for spreading your aura of empowerment and laughter; Shirin, my mindfulness guru; Soheila, for making me so much more structured; Soorej, for all the laughter; Wilton and William – Os echo de menos!

To the qualitative discussion group and to our splendid interdisciplinary gender breakfast club (sorry, I happen to be biased here).

To the staff at IMCH! To Kristin, Jenny, Hanna x 2 for all the help when needed, and special thanks to Karin, you have been my rock.

To Aileen, the best happy-boost-language editor ever!

To the ‘anti-stress group’, those Tuesday fikas at Güntherska have been so needed, so appreciated, so good.

To Amanda for all our chats and for all the chats to come; to Helle for your encouraging inputs; to Kristi for always cheering for me; to Netti for assuring my Swedish texts are flawless; to Rachel for assisting me in finding my way in the world of policy-research; to Sigga, so grateful that our PhD project brought us together.

To Malin, both on a professional and private level – I’m forever grateful that the Universe made you my neighbor.

And, last but not least:

To all of you – my Dearest Friends, my Beloved Family and my Patrik.
Thank you for all the encouragement and love – Ni betyder allt för mig.

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