

# **Traumatic episodes related to the genocide period, mental health effects and perceived barriers to care facing young adults in Rwanda**

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UNIVERSITY OF GOTHENBURG

Gothenburg 2016

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ISBN 978-91-628-9840-3 (print)

**ISBN:** 978-91-628-9841-0 (e-pub)

**Electronic Publication:** <http://hdl.handle.net/2077/41554>

Printed in Gothenburg, Sweden 2016

Ineko

Dedicated to my family, relatives and good friends

*“Not everything that can be counted counts and not everything that counts can be counted”.*

Albert Einstein

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## ABSTRACT

**Aims:** To investigate mental health status in a Rwandan population aged 20-35 years, their associations with traumatic episodes experienced during the 1994 genocide and life time, and barriers to care as perceived by health care professionals.

**Methods:** The cross-sectional population-based study was conducted using the Mini International Neuropsychiatric Interview tool to investigate prevalence of mental disorders and items from the Harvard Trauma questionnaire for traumatic episodes. The study was conducted during December 2011-January 2012 among 440 (48%) men and 477 (52%) women, residing in the Southern province of Rwanda. Simple and multivariable logistic regression analysis was used to identify risk factors associated with mental disorders. Six focus group discussions were further conducted with health care professionals to explore barriers to mental health care.

**Results:** Women were to a higher extent exposed to traumatic episodes than men during their lifetime but in the genocide period men and women were equally exposed. Traumatic episodes were to a limited degree reported to take place also in the past three year period (2009-2011). Those exposed to traumatic episodes during the genocide were 17 years later at risk of having no children, being less educated and living in poorer circumstances as compared to those not directly exposed.

The prevalence of mental disorders, such as depression, anxiety disorders, post-traumatic stress disorder and suicide risk was twice as high for women as for men. Traumatic episodes experienced in the genocide period and during lifetime were highly associated with current mental health status in both men and women. However, among women, exposure to current physical/sexual partner violence was as well strongly associated with all mental disorders under investigation, as was poverty for both men and women. Health care professionals perceived more barriers than facilitators to care. Poverty, poor family support, poor health literacy, gender norms and stigma negatively influenced mental health care seeking among men and women.

**Conclusions:** The prevalence of mental disorders in men and women in Rwanda was comparatively high, and higher in women than in men. People with mental disorder in Rwanda face several barriers to appropriate care. Mental health care should be integrated into primary care to improve accessibility and quality of care and number of professionals, i.e. psychiatrists, psychologists and mental health nurses needs to be raised. As long as traditional gender norms stigma and mental health illiteracy influence health care seeking behaviour, neither men nor women will receive appropriate care. Information, education and communication interventions are needed to address these issues.

**Keywords:** Population based, Traumatic episodes, mental disorders, barriers to care, content analysis, Rwanda.

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# SAMMANFATTNING PÅ SVENSKA

**Bakgrund:** I Rwanda pågick ett folkmord under tre månader 1994 som beräknas ha skördat 800.000-1 miljon människors liv och cirka 2 miljoner människor flydde landet. De som överlevde vittnar om svåra traumatiska upplevelser såsom att ha bevittnat massmord, hotats med vapen, behövt åse hur anhöriga utsatts för grovt våld och död, och hur närstående kvinnor och flickor våldtagits. Sådana händelser pågick även före 1994 men eskalerade i samband med politiska händelser under året. Varje familj i Rwanda har erfarenhet av sådant våld och den psykiska ohälsan som drabbade många har i olika studier visat sig kvarstå år efter år.

Syftet med denna avhandling var att undersöka förekomst av olika traumatiska upplevelser som drabbade människor i Rwanda i samband med folkmordet 1994, och hur dessa påverkat människors psykiska hälsa 17 år senare. Vidare undersöks hälso- och sjukvårdspersonals kunskap och erfarenhet av vilka barriärer till vård som män och kvinnor med psykisk ohälsa ställs inför. Studien undersökte även vilka traumatiska upplevelser som skett under hela livet samt under de tre senaste åren (2009-11) med utgångspunkt från det år då data samlades in, 2011-12.

**Metod:** En populationsbaserad, epidemiologisk studie som inkluderade 917 personer, 440 män och 477 kvinnor, har genomförts där data insamlades från slumpmässigt utvalda hushåll i den södra provinsen. I delstudie I undersöktes förekomst av traumatiska upplevelser hos män och kvinnor i befolkningen i åldern 20-35 år med hjälp av ett välkänt formulär (Harvard Trauma questionnaire) och i delstudie II undersöktes förekomst av psykisk ohälsa med hjälp av ett annat välkänt diagnostiskt instrument (MINI International Neuropsychiatric Interview). Samband mellan traumatiska upplevelser och psykisk ohälsa mättes i multivariabel logistisk regression, såsom risk rater med 95% konfidensintervall.

Två kvalitativa studier genomfördes med hjälp av fokusgruppsintervjuer med hälso- och sjukvårdspersonal som dagligen mötte och behandlade personer med psykisk ohälsa. Syftet var att undersöka barriärer till vård. De professionella arbetade på mottagningar för människor med psykosociala problem samt på distriktssjukhus. Sex fokusgruppsintervjuer genomfördes med sammanlagt 43 personer och materialet analyserades med hjälp av innehållsanalys.

**Resultat:** De män och kvinnor som deltog i studien var 3-17 år då folkmordet inträffade 1994. Så många som 73% av männen och 84% av kvinnorna rapporterade förekomst av någon eller flera av de 16 traumatiska händelser de tillfrågades om. Under folkmordsperioden var det 38% av männen och 35% av kvinnorna som direkt upplevde svåra traumatiska händelser. Förekomsten av psykisk ohälsa, manifesterad som depression, ångestsyndrom, posttraumatiskt stressyndrom och/eller suicidtankar var relativt hög i hela populationen men kvinnor rapporterade två gånger så hög förekomst som män. Ett klart samband kunde visas med upplevelser av traumatiska händelser under livet och under folkmordsperioden, även då man kontrollerade för andra faktorer som även de hade statistiskt signifikant samband med mental ohälsa, såsom fattigdom och för kvinnor erfarenhet av partnervåld.

I de kvalitativa studierna tillfrågades hälsopersonal om sina erfarenheter av barriärer till vård. Det framkom ett flertal barriärer till psykiatrisk vård, såsom fattigdom och dåligt stöd från familjen, rädsla för stigmatisering, dålig medvetenhet i befolkningen om psykisk ohälsa och en övertro på traditionella hälsoarbetare och böner samt små resurser till psykisk ohälsa. Vidare så präglades mäns och kvinnors vårdsökande av en allmän uppfattning i samhället om mäns styrka och förmåga att själva lösa sina hälsoproblem medan kvinnor sågs som svagare och därför behövde mera vård.

**Konklusioner:** Trots att 17 år gått sedan folkmordet så präglades många av de traumatiska upplevelser de bar med sig och många led av psykisk ohälsa som en konsekvens. Psykiatrisk vård behöver bli mer tillgänglig och lämpligt vore om sådan vård kunde decentraliseras till hälsocentralsnivån för att öka tillgänglighet och kvalitet. Fler psykiatrer och psykologer samt mentalsjuksköterskor behöver utbildas. Information och utbildningsinsatser behövs riktade till befolkningen för att öka kunskapen om psykisk ohälsa och motverka den stigmatisering som drabbar människor med psykisk ohälsa.









# LIST OF PAPERS

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

- I. Rugema L, Mogren I, Ntaganira, J, Gunilla Krantz K. Traumatic episodes experienced during the genocide period in Rwanda influence life circumstances in young men and women 17 years later. *BMC Public Health* 2013, 13:1235  
doi: 10.1186/1471-2458-13-1235, Open Access
  
- II. Rugema L, Mogren I, Ntaganira, J, Gunilla Krantz K. Traumatic episodes and mental health effects in young men and women in Rwanda, 17 years after the genocide. *BMJ Open*. 2015 Jun, 24;5(6):e006778.  
doi: 10.1136/bmjopen-2014-006778. Open Access
  
- III. Rugema L, Krantz G, Mogren I, Ntaganira, J, Persson M. "A constant struggle to receive mental health care": health care professionals' acquired experience of barriers to mental health care services in Rwanda. *BMC Psychiatry*. 2015 Dec, 16;15:314.  
doi: 10.1186/s12888-015-0699-z. Open Access
  
- IV. Rugema L#, Persson M#, Mogren I, Ntaganira, J, Krantz G. Strong gender norms and stigma negatively affect marital stability and access to mental health care in people with mental disorders: A qualitative study from Rwanda. Manuscript submitted for publication.

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# ABBREVIATIONS

AAAQ	Availability Accessibility Acceptability and good Quality care
CA	Content Analysis
CDC	Center for Disease Control and Prevention
CHW	Community Health Workers
CMD	Common Mental Disorder
DALY	Disability Adjusted-Life Years
DSM	Diagnostic and Statistical Manual of Mental Disorders
EICV	Integrated Household Living Survey
FGD	Focus Group Discussion
GAD	Generalized Anxiety Disorder
GDP	Gross Domestic Product
GK	Gunilla Krantz
HIV	Human immune virus
HTQ	Harvard Trauma Questionnaire
IM	Ingrid Mogren
IRB	Institutional Review Board
JN	Joseph Ntaganira
LR	Lawrence Rugema
LMIC	Low and Middle-Income Countries

MDE	Major Depressive Episodes
MINI	Mini International neuropsychiatric interview
MMI	Military Medical Insurance
MP	Margareta Persson
NCD	Non communicable diseases
PhD	Doctor of Philosophy
PTSD	Post-Traumatic Stress Disorder
RAMA	La Rwandaise d' Assurance Maladie
RDHS	Rwanda Demographic and Health Survey
RPF	Rwanda Patriotic Front
RwVMHBC	Rwanda violence mental health and barriers to care project
SPH	School of Public Health
UHC	Universal Health Coverage
WHO-CIDI	World Health Organization-Composite International Diagnostic Interview
YLD	Years Lived with Disability

# DEFINITIONS IN SHORT

Common mental disorder  
(CMD)

In this thesis CMD refer to depression, PTSD,  
GAD and suicide risk



# 1 INTRODUCTION

## 1.1 Mental health

## 1.2 Global perspective

The 2010 update on global burden of disease found that mental and behavioural disorders contribute to 7.4 percent of global Disability Adjusted Life Years (DALY), and major depressive disorder carries the heaviest burden, accounting for 2.54 percent of all global DALYs (1). The global burden of mental disorders has increased by 37% between 1990 and 2010, and is the leading cause of years lived with disability (YLD) globally (1). The highest proportion of total DALYs occurs among the younger population, aged 10–29 years (1). In low and middle income countries (LMIC) mental health problems accounted for 11% of the disease burden in 2007 (2). Among people aged 15–44 years, unipolar depression is the second cause for women and third for men of disability-adjusted life years (DALY's) in LMIC (3–5). Depression alone makes a significant contribution to other non-communicable diseases such as cancer and cardiovascular diseases (5, 6). Further mental problems contribute to intended and unintended injuries among the youth population (7).

Most of the mental disorders affecting younger populations are depression, anxiety disorders, post-traumatic stress disorder (PTSD) and somatoform disorders, and these are together sometimes referred to as common mental disorders (CMD) (8). Apart from young people suffering from CMD, suicide attempts and suicide ideation remains a serious problem commonly occurring among women in LMIC and one of its risk factors is violence exposure (9).

In this thesis CMD refer to depression, PTSD, GAD and suicide risk. Reasons for CMD are many, some important factors related to young people are substance and alcohol abuse (10, 11), and violent conflicts in some parts of the world (12). The quality of life of people with depression and anxiety disorders is often poor (13, 14). CMD were also found to be associated with other public health problems, such as poor maternal and child health as well as infectious diseases like HIV and AIDS, poor education and unemployment, worries about the future and how to form a family (2). Young people's social and economic life is seriously affected and their reproductive and productive capacity are hampered by CMD. Despite these serious

problems, mental disorders continue to attract minimal resources and attention from decision makers in LMIC leading to weak mental health policies on how to prevent, detect and treat such disorders (15, 16). A study among Cambodians show serious mental health problems and poor economic situation due to a number of traumatic episodes that many people experienced during the prolonged internal conflict that the nation has lived through (17). Likewise, the conflict in Iraq that displaced about 5 million people, brought serious adverse mental health consequences to its population (18).

Various studies in LMIC consistently indicate the association between common mental disorders and poverty or indicators of low social economic status, such as low education, being unemployed, lack of assets, lack of housing, low social class and food insecurity (8, 19-21). Prolonged conflicts most often lead to increased poverty levels, worsened socioeconomic conditions and negative influences on population health (17, 22, 23). Women compared to men are more affected by mental problems such as depression, and suicide behaviour due to various reasons, one of them is intimate partner violence perpetrated against women (24-26).

Mental health is a neglected problem with very little funding in LMIC (27). The World Health Organisation (WHO) recommends integration of mental health care into the primary health care (28-30). There are benefits of integrating mental health care into primary health care such as improved access for mental health care, avoiding continued fragmentation of services and reduction of stigma as well as improving care delivery of the entire health system (30, 31).

## **1.2.1 Mental disorders in Rwanda**

The disease panorama in Rwanda is still dominated by infectious diseases but chronic diseases are becoming more prevalent in the population. The burden of mental disorders is estimated to 3.54 DALY's/100,000 inhabitants (32). The genocide in 1994 gave rise to increased numbers of mental disorders among young men and women of different age groups in Rwanda (33, 34). Few if any studies exist on mental disorders in a population based sample undertaken before 1994.

Only a limited number of studies on mental health in Rwanda exist and these mainly report prevalence rates of PTSD and depression in the aftermath of the genocide in 1994. These studies show a continued high prevalence over

the years since 1994. A study performed five years after the genocide included 368 men and women with average age of 35.7 years and shows that the rate of current depression was 11% in men and 17% in women (35). Eight years after the genocide, another study investigated PTSD prevalence among 2091 people in different parts of Rwanda and found that 25% fulfilled the criteria, however data were not sex-disaggregated (36). Fourteen years after the genocide, a study on PTSD was performed on 962 people, aged 16-34 years of age, using a diagnostic tool the Mini International Neuropsychiatric Interview (MINI) instrument. The prevalence of PTSD in women was 21% and in men 30%, with a total sample prevalence of 26% (37). Lastly, a study conducted 15 years after the genocide, including 114 genocide survivors of mean age 47 years, found that 46% suffered from PTSD, 59% from anxiety and another 46% from current depression (33). A genocide survivor refers to a person who was in the country and survived during the three months of mass-killings.

These examples illustrate the difficulties encountered when comparing findings from studies conducted with different instruments on differing age and population groups with varying sample sizes. In all cited studies, however, the mental disorders investigated were associated with traumatic episodes experienced during the genocide period. Of note is that a steadily decreasing trend in mental suffering over time was not found as could have been expected due to the elapsed years after the genocide and subsequent repression of memories. From this, the conclusion to be drawn is that the horrors that took place during three months in 1994 severely influence peoples' mental health status 15 years later, but it is difficult to draw any conclusions on whether the prevalence shows an upward or downward trend.

In Rwanda, annually on 7<sup>th</sup> April, the genocide commemoration period starts country wide. The idea is to honour the deceased and reflect on what happened to avoid re-occurrence. However, it could be that this general approach of regularly reminding of the horrors in 1994 makes people fall back into memories and experience difficulties in leaving behind what happened.

Studies have also been performed on perpetrators of violence in the genocide period and later. In one study, structured interviews were conducted among 269 imprisoned perpetrators of genocide (66% men) (33). It was found that a significant number of perpetrators met the symptom criteria for PTSD (46%), and anxiety symptoms were commonly occurring (59%) (33). This shows that perpetrators of mass killings were traumatized by their own actions in Rwanda (33, 38).

It is acknowledged that children of mentally ill parents are at risk of being affected by various symptoms due to their parents' compromised capability to take good care of them (39). According to Stab, children of Tutsi returnees, who returned to Rwanda from neighbouring countries after the 1994 genocide, saw devastated families and as a result they suffered various mental disorders (38). Children of the thousands of Hutu people who fled Rwanda to the Democratic Republic of Congo during or after the 1994 genocide, and children of the imprisoned perpetrators were as well at risk of mental disorders (33).

It was also documented that thousands of women were raped and infected with HIV, and being HIV positive was found to be a risk factor for mental problems (40). A study of 850 women (658 HIV-positive and 192 HIV-negative) conducted in 2009 in Rwanda, indicated that HIV positive women had higher prevalence of depressive symptoms than HIV negative infected women, with 80% of HIV positive women suffering from depressive symptoms (41).

According to WHO, suicide rates in Rwanda are 12% per 100,000 people, 17% for men and 7% among women in 2012 (42). Among other reasons, having been convicted of genocide related crime was highly associated with suicide as these people continue to experience psychological distress (43, 44).

From other studies performed within this research programme (45, 46), and from earlier studies performed in Rwanda and elsewhere, it is a well-known fact that physical, psychological and sexual intimate partner violence perpetrated against women is associated with various mental disorders, such as depression, PTSD, suicidality, generalized anxiety disorders (47, 48). Evidence also shows an elevated risk that men exposed to intimate partner violence will suffer from CMD (46, 47). However, the severity of the violence and its psychosocial consequences are far greater for women than for men experiencing partner violence (46). The psychosocial impact of violence is found to be associated with being female and nature of the violence (49-51).

## **1.2.2 Intergenerational effect**

The possibility of an inter-generational effect, where the symptoms of the traumatized parents are transferred to their children even when the children

never experienced the trauma themselves is being discussed (39). An intergenerational effect may be at hand based on attachment theory (traumatized parents' relative inability to create a secure attachment during the child's early years), or psychosocial stress theory (transmission of stressful social environments due to parental trauma) (52-54).

The many robust findings of young children at the time of the genocide that still suffer from mental disturbances years after the trauma exposure, lend support to such an attachment hypothesis (36, 37, 55-57).

However, a study, conducted among 125 Rwandan mothers suffering from PTSD and their children, was performed to establish whether this was associated with symptoms of anxiety and depressive disorders in their children (58). The results showed no trans-generational trauma in these children, but rather a significant negative health outcome due to their own exposure to family violence during their childhood (58). This underscores the importance of investigating current or more recent explanations to ill-health in children than effects of the genocide.

## **1.3 Rwanda**

### **1.3.1 Country Description**

Rwanda is a small, low-income country in central Africa with approximately 12 million inhabitants (59). The surface area is 26 thousand sq. km, there is a high population density across the country, 395 inhabitants per square kilometer in 2010 (60). It has no access to the sea, i.e. it is landlocked and with few known natural resources (61-63). The main export products are tea and coffee, further tourism is an important source of state income (64). The majority of the people (80%) live in rural areas (65), and depend on subsistence farming for their livelihood (60).

**Map of Rwanda with boundaries of its five provinces**



*Figure 1. Map of Rwanda showing its geographic location in Africa and boundaries of the five provinces. Source: DHS report 2010 (60).*

The country is known as the “Land of a Thousand Hills” because of its hilly nature, where crops are grown in terrace-like formations (60). It is a republic led by a president and is administratively divided into five provinces, Northern, Southern, Eastern, Western Province and Kigali capital city, each led by an appointed governor as the administrative head (61). The four provinces are further sub-divided into 30 districts (66), each led by an appointed mayor as the administrative head.

Rwanda’s total trade amounted to US\$ 615.9 million in 2015, exports were US\$ 97.5 million while imports amounted to US\$ 478.7 million (59). Its gross domestic product (GDP) per capita was 644 US\$ in 2012 but five years earlier it was 371 US\$ in 2007 (67). Since the last decade the economy has grown at an average rate of 12.5% per year (64). The county has improved its sources of drinking water and now clean water is accessible to 74% of households and about 5% have their own running water in their courtyards (60).

Although Rwanda has a history of genocide, life circumstances have changed drastically since 1994. The country has developed into a society with economic growth and a certain degree of social development and social protection of the population (68). As of 2009, enrolment in basic primary education had risen to 96%, a higher enrolment for girls than for boys (97.5 and 94.3%) was realized, but 11.4% dropped out and did not finish primary education (69). According to the Rwandan Third Integrated Household Living Survey (EICV-3) of 2012, Rwanda’s literacy rate was 83% for those aged 15-24 years, but less (69.7%) in the population aged 15 years and above (66). About 83% of the population, aged 6 years or more, reported ever having attended school (66). However the proportion of girls, aged 13 to 18 years attending secondary school remains low compared to boys, and it was shown that for every two boys attending secondary school, there was only one girl (66). Generally, literacy was higher among the youths due improved access to education but it was still lower among the lowest quintile of the socio-economic groups in the population (66).

### **1.3.2 Organisation and management of the health system**

Community Health Workers (CHW), play a crucial role in Rwanda's health system, they actually form the first line in the health system. Every district is served by a group of dedicated CHWs, there are at least three in every village, selected by the villagers based on integrity. Once selected they are offered basic training in health matters and they then offer health education, minimal preventive and curative services as well as family planning services to their community (70, 71).

The Ministry of Health decentralized health care services to the lowest unit of care, that is the health center level (72). A primary health care approach was adopted by the government based on the 1978 Alma Ata principles (73, 74). Each of the four provinces is further divided into districts and a district normally comprises five sectors, and include at least one hospital (75). While a district is estimated to include 250,000-500,000 inhabitants, a sector includes approximately 50,000 people and commonly has one health centre to take care of people's immediate health needs, but also preventive activities, such as maternal and child health care, immunisations etc. (75).

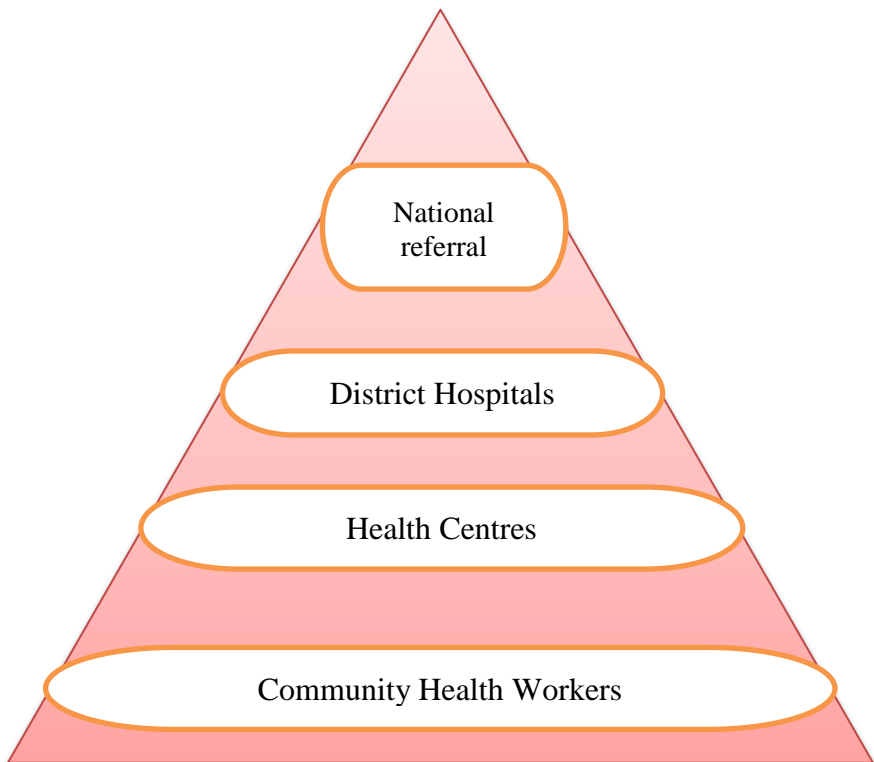
Hence, the entry point to health care for community members is the health center and this refers more complicated cases to district hospitals. A national referral hospital is found on the outskirts of the capital city Kigali, which offers the most advanced level of care in the country (72).

Despite the commitment of the Ministry of Health of Rwanda to provide mental health care, among other things by increasing human resources for mental health (76), scarcity of mental health care personnel is a reality. Especially psychiatrists remain few and only five were available in the country in 2011 (0.05/100.000 inhabitants) and the number of mental health nurses is also scarce (1.3/100,000 inhabitants) (77). District hospitals are staffed with a mental health nurse and occasionally also with a clinical psychologist, while no trained mental health worker is found at the health center level (78). There are two government-run specialized mental health facilities also located in cities (Kigali and Ndera located on outskirts of Kigali) (76), and additional units are run by charity organisations (79). Most mental health services are located in or near urban areas, which makes access to services limited to rural populations, while urban populations benefit in terms of geographical accessibility (80).



The Government is committed to train more health care professionals (76). In 2010 there was one medical doctor for every 18,332 people and one nurse for every 1,493 people yet the ratio of mental health nurses was only one for every 100.123 people (65). Due to the concentration of tertiary medical care in the capital city, the majority of doctors and nurses are also based in urban areas (65).

**Rwandan Health administrative decentralized structure**



*Figure 2. Adopted from Nathan L. et al. & Drobac P. et al. (70, 72)*

### 1.3.3 Health indicators

The average life expectancy of Rwandans born today is 66.7 years, for men it is 62.6 years and for women it is 66.2 years (81). According to the Rwanda Demographic and Health Survey (RDHS) 2014-2015, Rwanda's current maternal mortality ratio is 210 deaths per 100,000 live births, the infant mortality is 32 deaths per 1,000 live births while under-five mortality rate is 50 deaths per 1,000 live births (82), compared to RDHS of 2005, ten years earlier when under-five mortality was 203 per 1000 live births (61). In relation to neighbouring countries, these mortality figures are low. For example, Uganda's, maternal mortality ratio was 438 deaths per 100,000 live births, its infant mortality rate was 52 deaths per 1,000 live births and the under-five mortality rate was 90 deaths per 1,000 live births in 2011 (83). The fertility rate of an average Rwandan woman was 4.2 children in 2014 (82). One explanation for this improvement is the wider coverage of community based health insurance (further described below), another is the work performed by community health workers (CHWs).

Only 2.4% of the Rwandan population is projected to be 65 years and above in the middle of 2016 while 25% will be between 5-15years and 47% between 15-49 years (59). The country has a young population which, among other factors, is caused by the still dominating disease panorama of communicable diseases which make average life expectancy generally lower in many Sub-Saharan Africa countries (84). The HIV prevalence remains stable at 3% among adults aged 15 to 49 years (60). There is yet to be a population based survey to indicate prevalence of non-communicable diseases (NCDs) in the country. However, data available suggest that at least 51% of outpatients' consultation in district hospitals were attributed to NCDs in 2013 (85).

The national budget for mental health is estimated to 400 million Rwandan Francs per year (approx. 510,000\$ at current exchange rate). The amount includes donor organisations' assistance to mental health programmes but figures for the absolute total expenditures on mental health programmes by government are not available because funds are decentralized and infused into hospital budgets (77). Although Rwanda still has minimal financial resources allocated to health (62), the government initiated a health insurance scheme referred to as *Mutuelle de Santé*, to finance health care enabling people easy access to health services without being depleted of resources (86). This boasts Rwanda as one of the few, if not the only country in the East African community, with a community based health insurance scheme that covers over 85% of its population (86, 87). In 2010, 78% of Rwandans

were under health insurance, of these close to 98% of the households were insured with *Mutuelle de Santé*. Other prominent insurances are La Rwandaise d'Assurance Maladie (RAMA), Military Medical Insurance (MMI), and other private insurance companies mostly used by city dwellers (60).

### **1.3.4 Gender aspects in Rwanda**

The constitution in Rwanda provides that at least 30% of elected senators in parliament are women (88), as a result 56% of lawmakers are women (89). Legally, women have the right to inherit assets according to the 1999 property law reform (90). Gender based violence is outlawed in Rwanda (91). The Government of Rwanda has put in place facilities to provide information, health services and legal support to female victims of partner violence, so called One Stop Centers, where abused women and men can seek shelter. There is further a One Stop Centre in Kigali's police hospital which provides psychosocial support, medical and legal support to victims of violence, for severely abused women to be able to report directly to the police while being in hospital for treatment. The challenge for women however, is to take the decision to report the violence considering the, sociocultural and economic constraints that will follow (92).

However, while the existing laws provide for equal rights between men and women, there remain sociocultural constraints affecting gender equality in everyday life, with women being in an inferior position, with less decision-making capacity, particularly in rural based households. Gender roles are traditional with women being considered as mainly responsible for household chores, which deprive them of economic opportunities and make them dependent on their husbands for basic needs (92). In addition, women's inferior position and lack of personal income make them vulnerable to perpetual violence from their partners (92).

## **1.4 Traumatic episodes in internal conflicts**

### **General overview**

*Traumatic episodes* are defined as trauma and torture linked to mass violence (93). Internal conflicts have increased in recent decades, their escalation have exposed civilians, both men, women and children, to severe proportions of atrocities (94). In the Yugoslavia and Darfur conflicts, rape was used as a weapon to destabilize societies, break down relationship and disintegrate

family ties to humiliate targeted groups of people (95-98). Mass conflicts are of great concern to those exposed and their close relatives and friends because of the long term impact on health (95, 99, 100). In Sub-Saharan Africa, a number of internal conflicts have taken place in the past 40-50 years, as in Uganda, South Sudan, Burundi, Sierra Leone, The Democratic Republic of Congo, South Africa to mention some of these conflict ridden countries. There is a body of evidence from these documented conflicts that people exposed to wide range of traumatic episodes suffer severe health problems, mentally and physically, with long-lasting effects. For example, in northern Uganda over two million people were internally displaced by the civil conflict (101). A study in 2006, involving 1210 adults living as internally displaced people, showed that 58% had experienced displacement, rape or sexual abuse of women and girls but also boys, lack of food or water, and as a consequence, the studied population showed high levels of psychiatric morbidity (101-103).

### **1.4.1 The 1994 Genocide against the Tutsi in Rwanda**

There were repeated waves of violence in Rwanda as early as 1962 when the country became independent from the Belgian colonial power (104). Prior to that, in the year 1959, there had been a Hutu revolt and as a consequence about 50,000 Tutsis were killed and others fled to neighbouring countries (105).

In 1990, children of refugees who fled the 1959 violence took up arms under Rwanda Patriotic Front (RPF) and launched a protracted armed attack that lasted for almost five years (38). The most horrendous wave of violence in the country reached its climax during three months in the 1994 genocide against the Tutsi (106, 107), when 800,000 to 1 million people, mainly Tutsis but also moderate Hutus were murdered by extremists (33). More than two million people fled their homes to neighbouring countries (108). In this period that lasted from April to July 1994, approximately 10% of the Rwandan population was wiped out (109). Several thousands of women were sexually humiliated (110, 111), and intentionally infected with HIV infection (112, 113). The children, adults and the elderly who survived the mass murder experienced horrific traumatic episodes such as mass killings, rape, witnessing rape, forced to fleeing from their homes, hiding under corpses to survive killings and sexual mutilation (33, 55, 114). Other episodes were

being robbed or threatened with a weapon, imprisonment of a close family member or witnessing unnatural deaths of close relatives (36, 55).

The genocide ended when the RPF defeated the government army and subsequently took over the capital city Kigali, on 4<sup>th</sup> July in 1994. Since that time, the current government has promoted reconciliation and aimed to reduce gender discrimination, especially important within education (38). To date, the Rwandan society is affected by the genocide as almost every family either lost a loved one or has a relative in prison or a former inmate (55).

Researchers have suggested theories to explain why one group of Rwandan people tried to eradicate their fellow countrymen in the 20<sup>th</sup> century. Each type of explanation given has a certain degree of basis in reality but is not without some blind spots. One explanation given to why the genocide was possible in Rwanda, is the extreme form of obedience of the people to their leaders. It has been described how there was total control and domination of the masses by their leaders, and people were obedient. Even after the disintegration of the Rwandan monarchy and after getting independence, people's attitude towards authority did not change towards critical independent thinking of matters of national importance (106). The intrusive state regulation and social control of all spheres of life, paved way for massive participation of the people in the killings (115). But some researchers have questioned whether this was obedience or internalization of orders and coercion to commit mass atrocities (obedience out of fear) (116, 117).

Secondly, Rwanda was vulnerable to colonial and neo-colonial influence and manipulation. Germany's early account was that Tutsi people were not indigenous Rwandans as the Hutus and the Twa people. In addition, the Belgians for administrative simplicity put ethnicity in the national identity cards, that was maintained until 1994 (118). Such racial marks among other factors facilitated mass selective killings (118). In the immediate years prior to the genocide, Rwanda was experiencing political tension and undergoing economic crisis (119). The International Monetary Fund and World Bank requested austerity measures, which threw the population into poverty as civil service salaries were shrinking (119, 120). The planners of the genocide exploited every frustration of the Hutu majority by portraying the Tutsi minority and moderate Hutus as the causers of such misery (120). It was under such a tense environment that the current President Juvenal Habyarimana's plane was shot down on its way back from Tanzanian peace talks, immediately the civilian slaughter by the presidential guards started in the capital city and this was the beginning of the genocide in Rwanda (107).

It has been suggested that the army led the killings in the capital Kigali (121); while militias and Interahamwe (a Hutu paramilitary organisation) executed killings in the villages (122).

To deal legally with genocide suspects, the government established home grown Gacaca courts, which are community based courts (33, 123, 124). This system tried suspects locally by allowing members of the community to participate as witnesses to give testimonies. During the genocide period in 1994, the infrastructure including health facilities was destroyed and the supply chain of medicines and consumables was stopped (71). Deterioration of public services specifically health services were devastating due to shortage of health care professionals, since they had been either killed or had fled the country to find safety in other countries (62, 71). Vaccinations services were almost stopped and less than one in four children was fully vaccinated against polio and measles in 1994 (125). After the genocide, the under-five mortality rate was the highest and life expectancy was the lowest observed in the country in the past 20 years (126).

Some of the displaced people settled in camps in neighbouring Congo but cholera outbreaks claimed thousands of refugees (127). The subsequent huge increase in mental health problems could not be met due to a severe shortage of psychiatrist, mental health nurses and clinical psychologist to give treatment and support (71). Severe economic consequences due to economic break down led to unemployment and difficulties for people to meet their basic needs (128).

There was political instability during the years that followed 1994 characterized by *abacengezi* (insurgents) infiltrating from the Democratic Republic of Congo and civilians lost their lives due to insurgents ambushes (129).

It is now more than 20 years since the genocide happened and the country has seen drastic change in terms of economic growth and a favorable health development as is explained above, however, the wounds from this period still exist in terms of mental health problems in the population.

## **1.5 Barriers to care and human rights aspects**

### **1.5.1 Universal health coverage**

People in low-income countries have less access to established health care services than people in high and middle-income countries. Within countries, the poorest people also have less access than those that are somewhat better off (130). As a working definition, access to health services is “the timely use of service according to need” (130).

Universal health coverage (UHC) means that everyone in society has access to the health care services without risking economic impoverishment (131). Universal Health Coverage, according to WHO, further means provision of accessible preventive, promotive, curative and rehabilitative health care services of good quality to all citizens, and is hereby closely linked to The Right to Health (132). UHC is firmly established in the WHO’s constitution of 1948 which states that health is a fundamental human right, but also in the Health for All agenda and Alma-Ata declaration of 1978 (132). To ensure UHC, availability, accessibility, acceptability of health services and quality of care must be guaranteed for all people (133). There are approaches used to determine if a country has attained UHC outlined in terms of rights, financial protection by enrolment in health insurance schemes, and the utilization of health care services (134).

In LMIC countries, the impact of poor funding to health care services has far reaching negative implications on mental health care services, which suffer from poor quality and lack of modern medicines, few qualified mental health care professionals and inability to decentralize mental health services to primary care, i.e. health-center level, partly due also to poor leadership (27). In many of the low and middle income countries, mental health services are not available in rural communities (135).

The unavailability of mental health services at the local level risks throwing young families into poverty. If trained professionals and modern treatment was available and more easily accessible, many young people would benefit and their families.

## **1.5.2 The right to health and Barriers to care**

Barriers to health care services relate to structural factors as well as to individual factors. The structural barriers are well described as the four interconnected critical elements; Availability, Accessibility, Acceptability of health services and Quality of care, referred to as AAAQ, further described below (136). These four elements constitute the concept of “*The Right to*

*Health*”, also understood as “The right to the highest attainable standard of health” (137, 138), which has been acknowledged in different international human rights documents such as in the Covenant on Economic, Social and Cultural Rights (137). The right to health further describes access to medical care and clean drinking water, sanitation, education and information about health including other related determinants of health without any discrimination based on age, sex/gender, sexual orientation, race, religion or disability (133, 137).

*Availability* means that health facilities, medical staff and health services as well as most required medicines are available in enough quantities. It includes as well determinants of health like clean water, sufficient sanitation, safe food and health information (137). *Accessibility* means that all required health facilities and consumables are accessible to everyone without discrimination. Means of transport should be readily available to any person in need of using health care and services should be integrated into the general health care (139). User fees should be affordable by everyone and poorer the population should not feel financially burdened. *Acceptability* means that health facilities and services must be respectful to medical ethics and be sensitive to culture, gender equality and observe confidentiality in relation to health care seekers. *Quality* of care means health services should be of good quality with qualified staff capable of providing safe and relevant medications (137). It is however, important to point out that these requirements have to be balanced towards the economic strength of each country, and should be incorporated into policy and planning processes of health services.

Barriers to care at the individual level can be reflected by life circumstances of an individual, like low educational level and/or low self-esteem (140), prevailing gender inequalities such as need for the husband’s, or any other relative’s, permission to seek health care services (141), other reasons that prevent women from going away from home (142), and the stigma attached to mental illness (7). Poor health knowledge, i.e. lack of information and poor experience of where and when to seek care in case one is ill (143, 144), loss of income or impoverishment due to health care seeking and lack of a someone to take care of the children while away, are additional barriers to care commonly experienced in Sub-Saharan African women.

Stigma related barriers due to mental disorders prevent people from seeking care for a treatable condition like mental illness (145, 146), thereby postponing early diagnosis and detection, and missing the benefit for early intervention (147). Self-stigma, ignorance of mental illness re-enforces stigma and fear among people with mental disorders (146). In addition, low



confidence of individuals with mental illness is underpinned by increased prejudice by people or statements made by health care professionals about people with mental disorders (146, 148). Individual values and beliefs such as religion and traditional healing play an important part in the health seeking process. People allocate a lot of time to prayers for help with their mental health problems, others seek care from traditional healers and resort to seeking professional care late or not at all (149, 150).

In conclusion, there are numerous barriers to accessing health services for people in low- and middle-income countries, and especially for the poor or marginalised groups. The access barriers relate to the health care services structures and organisation, which is mainly a Government responsibility (140). At the structural level, barriers are related to low prioritization of mental health that is mirrored in few resources allocated to support infrastructures that match with the proportional burden of disease and necessary interventions (151, 152). The individual determinants are factors influencing individual's ability to use health services (130). This differentiation is important to make as barriers require different interventions.

### **1.5.3 Barriers and facilitators to care in Rwanda**

In many Sub-Saharan Africa countries, Universal Health Coverage (UHC) continues to pose a challenge and many people struggle with out-of-pocket financial hardships for family members (153). The only study published that investigated health care seeking behaviour in a population based sample is a study performed within our research programme (154). Of 247 people with depression and/or suicidal thoughts, only six people sought professional care, while others preferred to ask for help and support from family and friends due mainly to accessibility and acceptability barriers to care, such as that health care services were difficult to reach or that proper treatment would not be given (154).

Rwanda is however one of the few countries on the continent with a Government initiated community based health insurance system (*Mutuelle de Santé*) and other private health insurances complement this and in total as many as 96% of the population were covered in 2012 (155). However, UHC still remains a challenge, due to the annual premiums and co-payments

charged at the point of care and restricted access to basic care especially for those in the informal sector, i.e. the extremely poor (158).

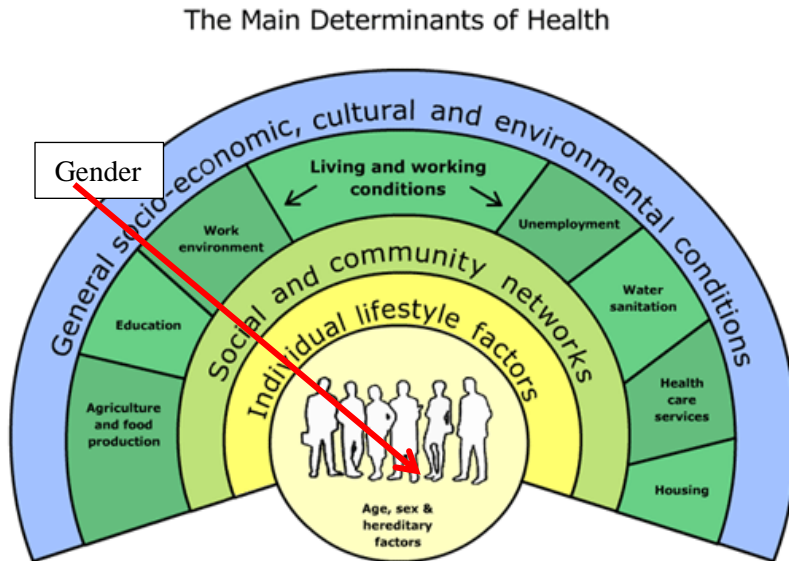
## 1.6 Theoretical framework

### 1.6.1 Public health science

This research project is grounded in *public health science*, a multidisciplinary science, in which determinants of health are analysed at four different levels in the societal organisation: the individual, the household, the community and the structural level including the interactions between the levels. Public health is mainly occupied with health of population groups and includes health promotion and health prevention, treatment of diseases as well as rehabilitation.

Public health is defined as “the science and art of preventing disease, promoting health and prolonging life through organised efforts of society”(156, 157). It means that the society, with its political, economic, social and cultural systems (the structural level), has a responsibility to offer its citizens an environment that makes a healthy life style possible (nutritious food, safe physical environments, possibilities for healthy leisure time activities, safe sex) but also that the citizens themselves have a responsibility to live a healthy life and are responsible for their choices. It also encourages research to investigate what *political, economic, social and behavioural factors are* responsible for observed inequalities in a society and the link between them. It is a *state responsibility* to develop and implement policies to reduce such inequalities, for example through welfare policies and other mechanisms within the powers of a state (158).

A theoretical framework below demonstrates how social determinants of health in a modern society can be understood at structural, community (living and working conditions), family (social and community networks) and individual levels of organisation (159) (see Figure 3 with different levels).



*Figure 3. Theoretical Framework that demonstrates layers of societal organisation modified by indicating how gender issues influence all levels in the model (159).*

## 1.6.2 Gender issues

Gender theory within public health describes how living conditions differ for women and men in terms of roles and responsibilities and access to and control of resources (160). In relation to access to and control of resources, women are in an inferior position in most settings and especially in many LMIC, which influences physical and mental health (92), and it is crosscutting across all different layers of the societal organisation (161). By integrating gender perspectives, the relationship between men and women, their differing life circumstances and the inequalities at hand becomes visible, with women being in an inferior position which often, results in poorer health for women than men (162, 163).

A wide body of literature on gender often shows how women are disadvantaged in terms of limited access to medical care and education opportunities in communities of low-income countries (91, 142, 164).

Women are the most affected by conflict due to lifelong damage of their reputation caused by rape and stigmatization (165), and they are the most affected by common mental disorders (CMD) (166). However, gender roles and relationships are not static (167), they should be analyzed in context and in relation to other social stratifying factors, such as age, race, social class and setting (168). Women from a social elite group may have more power and access to resources than a man belonging to a certain marginalized group, even when the society in which both lives does not embrace equal rights for women and men (169).

### **1.6.3 Epidemiology and Biostatistics**

Epidemiological principles and bio-statistical methods constitute the main tools in public health science although often supplemented with qualitative methodologies. A well-known definition of epidemiology is the one formulated by Last and reads as *Epidemiology is the study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems* (170). A quantitative study design is used when the health of a particular population is to be investigated. Epidemiological principles are applied to investigate the spread of a disease in a particular population, by using a random sample of people defined by certain criteria. Pre-formulated hypotheses are tested and either confirmed or rejected (171, 172). The method counts occurrences by estimating prevalence, frequency, and magnitude of health problems by generating numeric data. In doing this, it is possible to estimate the prevalence of a certain disease or condition in the study sample but in cases it is also possible to generalize the findings to the entire population in a country or region (173). Internal validity refers to how well one measure what is intended to be measured e.g. using the right research design and how variables of the study are measured to reflect health and other factors in the population of interest (172). External validity refers to the extent at which results of a study can be generalized to other populations not involved in the present study (172).

Related to the above are the potential biases in a study, e.g selection bias and measurement bias. Selection bias happens when the disease or factor under investigation is unavailable in the population selected for the study. Whether recall biases or measurement biases due to misclassification, they both may cause either exaggeration of association of the outcome with exposure or underreport the outcome of interest in a study (172).

## 1.6.4 Qualitative research methods

Qualitative methodology, on the other hand, is an exploratory way of generating novel insights, using inductive approach and observations to develop new hypotheses rather than hypothesis testing (174, 175). It seeks to explore perceptions and experiences, complex beliefs, values, range of its precursors, occurrences or phenomenon and motivations that underlie individual behaviours e.g. health behaviour (171, 176-178). The approach uses text-based data from open-ended or semi-structured discussions in natural settings, the data are culturally specific and often contextually rich (171, 173).

In qualitative research, trustworthiness of findings is judged in relation to the procedures applied to arrive at the findings (179). To increase the rigor of trustworthiness in a qualitative study four major criteria namely *credibility*, *transferability*, *dependability* and *confirmability* are critical (175, 180, 181). *Credibility* is about research focus and how well data and its analysis respond to the intended focus of the study. It takes into account selection of setting and participants, their experience and the data collection method used (179). Triangulation and sufficient time with participants (prolonged engagement) to capture their multiple realities is important to ensure credibility (182). Triangulation facilitates validation of findings by comparing findings from two or more sources, it refers to the application and combination of several research methods in the study of the same phenomenon (183). *Transferability* concerns the extent at which such results can be applied in other settings (referring to external validity or generalizability). The main rule is that findings cannot be applied in any other setting or to any other population. However, to allow transferability, the researchers should describe the context where the fieldwork was performed in such detail that the reader can decide whether any other research environment is similar and if so, the findings can be applicable also to that context (183). *Dependability* concerns the ability of a researcher to consistently account for changes in what is being studied in a particular research (182). It also means repeatability, in that using the same study design, the same study tool and applying it to same participants should produce similar findings. This is difficult and seldom done. *Confirmability* concerns the degree to which findings emerge from the data and not from the researchers own ideas, which means that the researchers have to distance themselves from their pre-conceived ideas of the phenomenon under study (182).

## **1.6.5 Thesis rational**

During the 1994 genocide in Rwanda, about 800,000 people were killed and many others experienced horrendous acts of violence (33, 106, 111). The consequences of the acts of the genocide gave rise to high numbers of mental disorders among young men and women in Rwanda (33-35). Yet, earlier studies performed in different periods after the genocide focused on a few mental conditions and especially on PTSD (33, 34, 36, 37, 57, 114) and a few on depression (184, 185). Study instruments were different and applied to different age groups and specific populations, all studies however indicate that irrespective of how many years after the 1994 trauma they were performed, the mental health effects were strong in the population under study. Uncertainty about the current magnitude and trend of various mental disorders warranted a study including several common mental disorders investigated by use of a validated instrument, the MINI International Neuropsychiatric Interview, in a general population based sample. To our knowledge this is the first population based study conducted in parallel with a qualitative study that interviewed health care professionals with hospital based knowledge and experience of mental disorders in Rwanda.

## **2 AIM**

The overall aim of the thesis was to investigate mental health status in a population aged 20-35 years, their associations with traumatic episodes experienced during the 1994 genocide and life time, and perceived barriers to care.

The prevalence and frequency of traumatic episodes were investigated in three different time periods, in 1994, life time and in the past three years (2009-2011). Barriers to seeking care for mental disorders were further investigated with gender differences and consequences as experienced by health care professionals.

The specific aims of the four studies:

### **Study 1**

To investigate prevalence and frequency of traumatic episodes experienced by young adults, 20-35 years old, during the genocide period, lifetime and in the past three years. Possible associations with socio-demographic and psychosocial factors were further investigated for long-term effects of such trauma.

### **Study II**

To investigate mental health effects of traumatic episodes experienced during the genocide period, i.e. 17 years later, but also associations between life time trauma and mental health in Rwandan men and women, aged 20 - 35 years.

### **Study III**

To explore health care professionals' acquired knowledge and experience of barriers and facilitators that people with mental disorder face when seeking mental health care services in Rwanda.

### **Study IV**

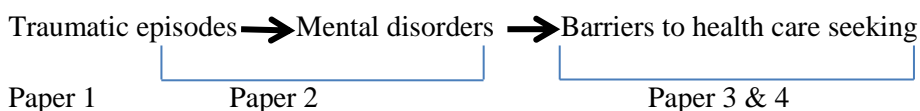
To explore gender differences in mental health care seeking as perceived by health care professionals' that are regularly counselling and treating people with mental disorders.

### 3 METHODOLOGY

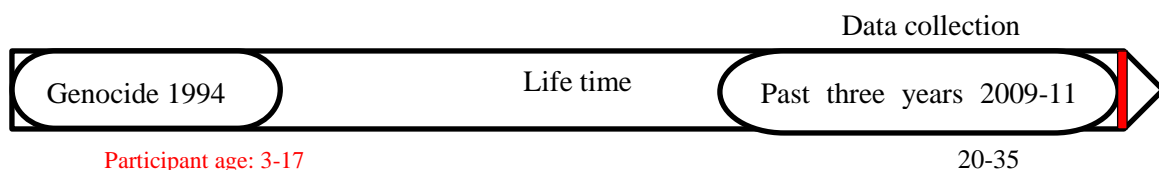
#### Overview of studies

This thesis is composed of two quantitative and two qualitative studies. Studies I and II were based on population-based data collected in the Southern province of Rwanda in December 2011- January 2012. Studies III and IV were based on focus group discussions (FGDs) with health care professionals working in mental health units and district hospitals, performed in October 2012.

This simple flow chart describes the main aim and indicates the various papers and their content.



Below in Figure 4 is an explanation of the relation between the data collection period, the three time periods investigated of traumatic episodes, and participant age.



*Figure 4. Time sequence from the genocide period to data collection period*

Table 1 below gives an overview of the study designs, main aims of the studies, analysis used for each study and participants of each study.



*Table 1. Overview of studies included in the thesis.*

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
<b>Study design</b>	Quantitative cross-sectional population based survey	Quantitative cross-sectional population based survey	Qualitative study	Qualitative study
<b>Data collection</b>	Face to face structured interviews	Face to face structured interviews	Focus group discussions	Focus group discussions
<b>Study sample</b>	Random population based sample of men and women (N= 917)	Random population-based sample of men and women (N= 917)	Facility based health care professionals (N=43)	Facility based health care professionals (N=43)
<b>Main aim</b>	To investigate prevalence and frequency of traumatic episodes and associated psychosocial effects in young adults 17 years after the genocide in Rwandan (Participants of age 20-35 years).	To investigate the mental health effects of traumatic episodes experienced during the genocide period, i.e. 17 years later, but also associations between life time trauma and mental health in Rwandan men and women, aged 20-35 years.	To explore health care professionals' acquired knowledge and experience of barriers and facilitators that people with mental disorder face when they are seeking mental health care services in Rwanda.	To explore gender differences and their consequences in mental health care seeking as perceived by health care professionals who regularly counsel people with mental disorders.
<b>Main method of analysis</b>	Descriptive statistics, simple and multivariable logistic regression analysis	Descriptive statistics, simple and multivariable logistic regression analysis	Content analysis	Content analysis

## 3.1 Qualitative studies I and II

### 3.1.1 Study design and population

The cross-sectional population-based study was conducted between December 2011 to January 2012 among 440 (48%) men and 477 (52%) women, residing in the Southern province of Rwanda, aged 20-35 years. The province has an estimated population of 2.226.000 people. The sample size

was based on the prevalence of depression (20%) in men and women in Rwanda (35). To detect a 1.5 fold risk increase of depression, with 80% probability, the sample size was estimated to be almost 900 people after taking 10% non-responders into account (35).

A questionnaire was designed mainly based on previously validated instruments. It contained items on traumatic episodes, physical and mental health, access barriers to care, and items on intimate partner violence (these were only used as control factors in this thesis). The questionnaire was translated into Kinyarwanda and back translated by a professional language translator before applying it in the field.

Multi-stage random selection of participants was performed, applying the nation-wide demographic health survey procedures to identify households for inclusion in the survey. The Southern province was randomly selected for the data collection. Out of the total number of 3512 villages in the eight districts, 35 villages were randomly selected, representing 1% of the total number of villages in the Southern province. The number of households for inclusion in each village was proportional to the total number of households in each of the selected villages. Upon arrival in each of the randomly selected villages, a central point of the village was sought under the guidance of the village chief. From the center of the village the nearest household was identified for interviewing the first eligible respondent, aged 20-35 years.

Female enumerators interviewed females and male enumerators interviewed males. The participant chose her/his place of preference for the interview. If a female was chosen from the first house, the next participant was supposed to be a male. In case a participant was missing from a selected household, the interviewer returned a maximum of three times on different days before considering it a missing case. In case there was no eligible participant in a household, the closest household was chosen. The reasoning behind this routine was that living conditions would possibly be similar to that of the primary selected household. There were two non-responses in the study; finally we had 917 respondents, 440 men and 477 women, aged 20-35 years with 99.8% response rate.

Due to the sensitivity of the questionnaire, only one participant was drawn from each household to observe ethics and ensure safety of each participant in the study. If there were more than one eligible participant in the household of the same sex, a lottery was applied to randomly choose one participant.

### 3.1.2 Data collection procedures

A team of 13 data collectors were recruited from the school of public health; they were all clinical psychologists, seven women and six men. They underwent a two day training to get a full understanding of the structured questionnaire and its intentions. A pilot testing of the questionnaire was carried out to test if the questions were comprehensible to our respondents, and only minor changes were necessary. For the fieldwork, two supervisors were appointed to guide the data collectors (LR and a colleague from School of Public Health). In each village, the village chief was contacted and the study was explained. Data was obtained through face-to-face interviewing by use of the developed questionnaire. The two field supervisors gave advice to the data collectors, pointed at selected households and checked questionnaires for internal non-responses. Data entry was done by four skilled clerks and supervised by one data entry specialist.

### 3.1.3 Instruments used

#### *The Harvard Trauma questionnaire*

To measure *Traumatic episodes* the Harvard Trauma Questionnaire (HTQ) was used (186). The instrument consists of four parts of which only Part I was used in this study. Part I asks whether a person witnessed or experienced different traumatic episodes, with a follow-up question on age at event. Other parts of the instrument include assessing feelings related to post-traumatic stress disorder (PTSD) as an effect of the trauma, but these were not used in this study (187). This instrument with all its parts has been used in several other post conflict regions and it has been validated in different populations and languages (188). According to the authors of the instrument, with careful adaptation to a cultural setting, the tool can be used to assess trauma in non-western populations (93, 186).

For this study, 16 items were selected from part I as deemed appropriate for the Rwandan situation out of a long list (42 items) of various traumatic episodes that may have occurred in an internal conflict situation (186). The selected 16 items focused on events that happened to oneself or a close person and relate to such experiences as mass murder or sexual violence, while items such as lack of water and shelter were not included. This shorter

version of Part I has not been validated specifically for this study since each of the items was asking only whether a certain traumatic episode happened or not, with a simple 'yes' or a 'no' response, and were not intended to measure a more complex concept. Therefore, then the number of episodes experienced were converted into a summary index.

Traumatic episodes were investigated for three different time periods, life time, the genocide period and past three years. The life time period embraces the period since childhood to the time of the data collection, December 2011 – January 2012. The participants in this study were 3-18 years of age at the time of the genocide in 1994. The traumatic episodes related to the genocide period (1994) included all cases reported in the period  $1994 \pm 1$  year to take care of recall bias of the exact age at exposure. This procedure was found important as age at episode was inquired about and not the exact timing (year) of each episode. As 17 years have elapsed since the genocide period in 1994 and some of the participants were really young then, it is plausible that some were unaware of their exact age, as evidenced in other studies (189). The period past three years concerns traumatic episodes that happened three years before data collection, i.e. the period between 2009 and 2011. The idea was to see if any such traumatic incidents still happen in Rwanda, 17 years after the genocide.

The individual items are presented in detail in Tables 3 and 4, in Paper I. These variables were used as dependent variables in paper I and as main independent variables in paper II (lifetime and genocide period).

### ***MINI International Neuropsychiatric Interview***

The WHO Mini International Neuropsychiatric Interview (MINI), a brief structured interview instrument to diagnose major psychiatric disorders, was used to estimate prevalence of mental disorders (190). This tool was constructed from the DSM-IV, version 6.0.0 and consists of 16 modules. The tool has similar validity and reliability properties as the WHO-CIDI instrument (191), but has the advantages of taking less time to use even by non-specialized interviewers, however health care professionals are recommended. It was recently evaluated in a study assessing several instruments to support the diagnosis of depression and found to have good sensitivity and specificity scores (192).

In this study, five modules were used to identify *major depressive episode current* as periods of depressive mood in the past two weeks and *major*

*depressive episodes past*, defined as earlier periods of depressive mood of at least two weeks duration; *suicide risk current*, defined as having suicide thoughts in the previous month; *posttraumatic stress disorder current*, defined as traumatic events in the previous month and *generalized anxiety disorder current*, defined as worried excessively or anxious every day of the last six months. These four mental disorders are referred to as common mental disorders in this thesis and used in paper II.

The MINI instrument uses one or more screening questions corresponding with the main criteria of the disorder. If the response was ‘no’ to all screening questions, the criteria for diagnosis were not met. If the response was ‘yes’ to any of the screening questions, further questions were asked, and at the end of each module the interviewer indicated whether the diagnostic criteria for a particular disorder were met or not.

### ***The WHO Women’s health and life experiences questionnaire***

This instrument was constructed by the World Health Organisation (WHO) and is titled Women’s Health and Life Experiences (193), a validated questionnaire across different cultures for research on intimate partner violence exposure (194, 195). It measures *spousal violence in the past year* by taking into consideration exposure to physical violence (six items) and/or sexual violence (three items). In this paper, it was used as control variable only. In one of our other studies, women were asked to indicate acts of violence that they had been exposed to from their current or earlier husband/partner and then physical and sexual violence exposure were combined. This variable was borrowed from this other study to be used only for control purposes in Paper II, as intimate partner violence exposure constitutes an important risk factor for mental problems.

## **3.1.4 Socio-demographic and psycho-social factors**

The socio-demographic and psychosocial variables included were *age, marital status, number of children, level of education and ever been to school*. Other characteristics included were *employment status, personal income, household income per month, source of income and social support*. To find a suitable variable that would mirror socio-economic status, a combined variable of various *assets in the household* were used (radio,

television set, mobile phone, computer, refrigerator, motorcycle, bicycle or car). These variables were dichotomized for use in regression analyses. Another variable constructed to mirror socio-economic difference was housing standard, but it failed to discriminate between population groups due to the rather homogenous housing standard in rural populations in Rwanda

### 3.1.5 Statistical methods

#### Study I

Prevalence of each traumatic episode was calculated and a summary variable was constructed for three time periods: lifetime, the genocide period and past three years. Data was sex-disaggregated and statistical significance for differences between men and women was obtained by use of Pearson's chi square test and Fischer's exact test.

Association between different traumatic episodes experienced during *genocide period* and *lifetime period* with socio-demographic and psychosocial factors were calculated by use of odds ratios (OR) with their 95% confidence intervals (95% CI). Variables that were statistically significant in the bi-variate analyses (crude associations) were considered for further analysis in the multivariable logistic regression analyses, in addition to age and in some cases also variables were included for theoretical reasons, such as proven importance in other studies. Variables controlled for were age, level of education, income and number of children. This resulted in minor changes of estimates.

#### Study II

The prevalence of mental disorders was calculated and experiences of traumatic episodes in life time and in the genocide period were used as independent variables. Associations between traumatic episodes in the genocide period and in the life time and common mental disorders such as *major depression current and past*, *suicidality*, *PTSD* and *general anxiety disorder* were calculated in simple and multivariable analyses, and presented as crude relative risk (crude RR) and adjusted relative risk (adj RR) with their 95% confidence intervals (CI 95%) for women and men. In this study, risk ratios were used instead of odds ratios due to some of the odds ratios reaching up to three times the odds of the unexposed for women. Re-

calculation to risk ratios then lowered the risks somewhat, but all variables kept their statistical significance in final models.

Multivariable logistic regression analyses were performed to control for age and to investigate possible additional covariates. Relative risk was estimated from odds ratios due to mental disorders being frequent in our study population (>10%) to avoid over-estimating the risk of mental disorders. Therefore we introduced a formula  $RR = OR/(1-Po) + (Po*OR)$  (196), where RR means adjusted relative risk, OR is adjusted odds ratio, Po shows the incidences of outcome of interest among the non-exposed.

As spousal violence showed strong associations with all mental disorders in another study within the RwVMHBC- project (45), it was decided to include this variable as a possible strong confounder for women. Physical/sexual spousal violence was not adjusted for in analyses on men as during the genocide period men were still too young for a stable relationship.

Recall bias is the lack of ability to accurately remember events that happened several years back (197). The Harvard Trauma questionnaire asked retrospectively participants' age at episode. The variable *genocide period* ( $1994 \pm 1$  year) was created for that purpose. This covered traumatic episodes that were reported in the period 1993-1995. As age at event had a potential for recall bias, this variable was created to minimize such bias. A further reason for including the years 1993 and 1995 was that in 1993 violations were to some extent ongoing and in 1995, peace had not yet been restored in all parts of the country due to insurgents from the Democratic Republic of Congo (198).

### **3.1.6 Qualitative studies Paper III – IV**

The two final studies in this thesis were explorative studies, using a qualitative approach with the aim to investigate barriers to care for mental disorders. As few such studies exist from low-income countries, it was decided to use a qualitative, hypothesis generating, method for data collection and analysis. The studies III and IV further added some understanding of why women reported higher prevalence of all mental disorders investigated in study II as compared to men (Table 2, paper II).

### **3.1.7 Study design and participants**

Focus group discussions were chosen for the data collection and content analysis as the method of analysis as the aim was to investigate perceptions and experiences among health care professionals, experienced in the field of meeting and treating people suffering from mental disorders.

In October 2012, six focus group discussions (FGDs) were conducted with health care professionals employed at mental health clinics and district hospitals. Health care professionals receive people with mental problems and were interviewed to shed light on barriers and facilitating factors as well as gender differences in health care seeking among people with mental disorders in Rwanda. The idea was to draw on the professionals' experiences of having met many young men and women suffering from mental ill-health to get their aggregated understanding, perceptions and experience on this matter. Manifest and latent content analysis were used for the analysis of the data (179).

### **3.1.8 Setting and selection of participants**

This study included three mental health facilities and three districts hospitals. The mental health facilities included one outpatients psychosocial center located in the capital city (Kigali central hospital), a mental hospital located on the outskirts of Kigali (CARAES Ndera) and a small mental health center in the Southern province (CARAES Butare, a branch of Ndera Main Mental Hospital). In addition, three district hospitals located in the Southern province were selected. The purpose of selecting both district hospitals and specialized mental health facilities was to include health care professionals with varied experience in the field of mental conditions, including both milder and more severe cases. A total of 43 subjects participated in the six FGDs, of whom 23 were females and 20 were males. There were 6-10 participants in each FGD. Of these, 28 had specialized training in mental health. The youngest participant was 26 years and the oldest was 59 years. Their average working experience within all kinds of health services was 6 years.

As an inclusion criterion, all health care professionals providing care to people with mental problems regardless of profession or length of work experience. This covered a range of different experiences, as some were specialized in mental health care while others were trained as general nurses but still provided mental health care.



In each facility, the manager of the facility was informed about the study and requested to assist in recruiting participants. Eligible participants were informed of the aim of the study and thereafter, asked if willing to participate. The manager of the health facility provided a calm room for conducting the FGD in each facility. Refreshments were provided during focus group discussions.

### 3.1.9 Interview guide

An interview guide was developed by the research team based on the objectives of the two studies. Prior to the data collection, a pilot test was made to ensure that the questions in the interview guide were clear. This exercise led to in minor corrections in the phrasing of some questions. A comprehensive introduction was made by the researchers to ensure there was a common understanding of the purpose of the study and the interview session. Examples of questions (Paper III) addressing the aim of this study were; *“From your professional experience, what do men and women do when they realize they suffer from a mental condition?”* and *“What barriers have you encountered among men and women as a reasons for not seeking health care? “In your opinion, what factors facilitate health care seeking for people with mental conditions?”*

Other questions (Study IV) focused on issues such as: *“From your professional experience, what do young men and women do when they experience mental disorders?”* *“What are the gender differences in health care seeking behaviour that you have observed?”* *“How would you explain such differences?”* In all the questions posed during the interview, probing questions were asked to extract more information from the participants covering barriers, facilitators and gender differences faced by people with mental disorders in Rwanda.

Interviews were carried out by a moderator (LR) and a co-moderator (colleague PhD student), in the presence of a note-taker (experienced staff in qualitative study) and an observer (MP). All FGDs were performed in Kinyarwanda. Interviews lasted between 65 - 135 minutes, on average 90 minutes.

After five FGDs, there was little new information given, but an additional FGD was conducted to confirm theoretical saturation. The recordings were transcribed verbatim into Kinyarwanda before translation into English. Some

parts of the translated transcripts to English were re-translated back to Kinyarwanda by a professional translator to check for discrepancy in meaning of the text in the two different languages.

### **3.1.10 Data analysis Paper III-IV**

Content Analysis (CA) was used to analyze the written material. CA is an approach originating from literary philosophy of social sciences and critical thinking (199). It was first applied in war propaganda during World War II (200), but over time it has become a generally applied analysis model common in the field of media research and in nursing science and in public health science (201). CA examines the manifest and the latent content in the material. The manifest content is the observable tangible body of materials as communicated by the participants, and the latent content, is the underlying meaning after interpreting the main content of the material (179). CA also focuses on the context, highlights the differences and similarities between and within codes as well as categories (179).

The focus group discussions were read through several times to get acquainted with the study material and to identify content areas (meaning units). The meaning units identified were in a next step condensed into codes. Once codes were in place, they were compared for similarities and differences and similar codes were brought together, resulting in sub-categories and categories. In a final step, themes were phrased mirroring the latent content or underlying meaning in the text. The main authors (RL and MP) identified content areas individually and suggested codes, and thereafter discussed until agreement was reached with co-authors (GK and IM). The entire research group finally agreed on all further steps and the final themes.

### **3.1.11 Ethical considerations**

This research project forms part of a larger project called “The Rwandan Violence, Mental Health and Barriers to Care Project (RwVMHBC). Two different tracks were investigated, in the project, the track chosen in this thesis concentrates on traumatic episodes, mental health and barriers to care (the other track focused on intimate partner violence). The study was approved by the National Ethics Committee of Rwanda (reference number

IRB: 00001497 of IORG0001100) for both the quantitative and the qualitative studies.

***Papers I and II***

Participation was voluntary and the respondents signed an informed consent form before an interview began. They were further informed about their right to withdraw from the interview at any moment in the research process until publication. There were no gifts or rewards given or promised to any of the respondents. Interviews were conducted by professional clinical psychologists, with sufficient experience of interviewing sensitive topics, such as traumatic episodes. The interviewers were instructed to support any participant who felt disturbed as a result of the interview. There was a car ready to assist in this endeavor if the situation warranted transferring a case to the hospital. However, no such case arose throughout the data collection exercise in the field. As a principal of confidentiality, participant's personal identities were not entered into the dataset, instead codes were used.

***Paper III and IV***

In the qualitative studies, no patient was discussed in a way possible to identify a single person. The participants were to a certain degree known to each other as they were employed at the same health facility, but no full names were used. Their identities do not appear anywhere in our data other than their socio-demographic characteristics. Quotes from the FGDs were anonymized. Permission to voice record was obtained from the participants.

## 4 RESULTS

### 4.1 Prevalence of traumatic episodes (Paper I)

#### Characteristics of Respondents

Our study population was homogenous in terms of socio-economic status and was living in relatively similar life circumstances, but clear gender differences were at hand as women were generally poorer than men. This was reflected in poor standard of living and in terms of assets available in the households. More women than men had not completed primary school (women 64.4%, men 58.7%) and more women than men were not in paid employment (Table 2).

**Table 2. Socio-demographic and psycho-social factors of the study population with p-values for difference between women and men. N=917.**

Variables	Total population (N=917)		Men (N=440)		Women (N=477)		p-value
	n	%	n	%	n	%	
<b>Age groups, years (n=908)</b>							
20-24	275	30.3	148	33.8	127	27.0	0.050
25-29	300	33.0	144	32.9	156	33.2	
30 -35	333	36.7	146	33.3	187	39.8	
<b>Marital status (n=912)</b>							
Married and cohabiting	578	63	236	53.8	342	72.3	<0.001
Widowed and divorced	35	3.8	2	0.5	33	7.0	
Single	299	32.8	201	45.8	98	20.7	
<b>Number of children (n=915)</b>							
No children	307	33.5	211	48.1	96	20.2	<0.001
1-3 children	467	50.9	192	43.7	275	57.8	
>3 children	141	15.4	36	8.2	105	22.1	
<b>Level of education (n=768)</b>							
Secondary school or University level	117	15.2	50	13.3	67	17.0	0.006
Complete primary or vocational level	178	23.2	105	28.0	73	18.6	
Incomplete primary	473	61.6	220	58.7	253	64.4	
<b>Ever been to school (n=915)</b>							
Yes	762	83.3	369	84.2	393	82.4	0.479
No	153	16.7	69	15.8	84	17.6	
<b>Employment status (n=913)</b>							
Full time paid employment	84	9.4	55	12.5	29	6.1	<0.001
Irregular or seasonal work	50	5.5	33	7.5	17	3.6	
No employment	779	85.3	348	79.1	431	90.4	
<b>Social support (n=917)</b>							
Good	592	69.6	301	68.4	291	60.0	0.086
Poor	258	30.4	114	25.9	144	30.2	
<b>Traumatic episodes, genocide period (n=916)</b>							
Not exposed	583	63.6	583	62.5	308	64.7	0.537
Exposed	334	36.4	334	37.5	168	35.3	
<b>Traumatic episodes, life time prevalence (n=916)</b>							
Not exposed	195	21.3	195	26.6	78	16.4	<0.001
Exposed	722	78.7	722	73.4	399	83.6	
<b>Physical and/or sexual violence , life time prevalence</b>							
No	771	84.1	419	95.2	352	73.8	<0.001

Yes	146	15.9	21	4.8	125	26.2	
<b>HOUSEHOLD CHARACTERISTICS</b>							
<b>Household monthly income (n=883)</b>							
17,500 RF or higher	189	21.4	86	20.5	103	22.2	0.566
Lower than 17,500 RF	694	78.6	333	79.5	361	77.8	
<b>Assets in household, sum measure (n=917)</b>							
Improved (at least one of the higher standard items)	654	71.3	323	73.4	331	69.4	0.189
Poor (none of the higher standard items)	263	28.7	117	26.6	146	30.6	

It was found that 37% of the men and 35% of the women had experienced at least one traumatic episode (mass killings, rape, forced to flee the home etc.) during the genocide period. However, women were more exposed than men over the lifetime period (83.6% women, 73.4% men). The most commonly reported traumatic episodes in men were having *experienced a life threatening injury, imprisonment, kidnapping, mass killings or being badly injured* and in women they were *being a refugee or forced to flee the home to escape danger, experiencing murder or unnatural death of a family member*. All other traumatic episodes were found to be of similar magnitude in men and women over the lifetime period.

**Table 3. Prevalence of various traumatic episodes experienced during life time, in 1994 and in the past three years, for men and women, presented with p-values for sex difference in lifetime estimates. N= 917, men 440; women 477.**

Traumatic episodes related to the genocide period, mental health effects and perceived barriers to care facing young adults in Rwanda

Traumatic events	Men Life time		Women Life time		p-values differene lifetime	Men 1994+-1year		Women 1994+-1year		Men past 3 years		Women past 3 years	
	N	%	N	%		N	%	N	%	N	%	N	%
1. Imprisoned, kidnapped, held captive	69	15.7	25	5.2	<0.001	3	0.7	5	1.0	21	4.8	6	1.3
2. Been a refugee, forced to flee from home to escape danger/ persecution	96	21.8	132	27.7	0.055	56	12.7	64	13.4	4	0.9	5	1.0
3. Experienced forced separation from family members	19	4.3	35	7.3	0.122	6	1.4	12	2.5	1	0.2	2	0.4
4. Experienced a life-threatening injury	80	18.2	53	11.1	0.001	13	3.0	16	3.4	14	3.2 *	5	1.0 *
5. Experienced a murder or unnatural death of a family member or a friend	99	22.5	124	26.0	0.248	37	8.4	47	9.9	10	2.3	9	1.9
6. Robbed, mugged, threatened with a weapon	75	17.0	82	17.2	0.930	10	2.3	21	4.4	14	3.2	16	3.4
7. Experienced imprisonment of close family member	206	46.8	248	52.0	0.129	39	8.9	35	7.3	26	5.9	29	6.1
8. Witnessed a traumatic event to a loved one	136	30.9	170	35.6	0.093	17	3.9	24	5.0	29	6.6	30	6.3
9. Ever been raped by a stranger	5	1.1	17	3.6	0.011	1	0.2	1	0.2	0	0	1	0.2
10. Ever felt forced to have sex in exchange of money or other benefits?	6	1.4	25	5.2	0.001	0	0.0	1	0.2	3	0.7	2	0.4
11. Witnessed repeated violence between family members	25	5.7	49	10.3	0.011	7	1.6	6	1.3	4	0.9	7	1.5
12. Witnessed physical/ sexual violence against a family member by someone outside of the family	18	4.1	36	7.5	0.034	3	0.7	6	1.3	3	0.7	8	1.7
13. Witnessed someone being badly injured or killed	43	9.8	88	18.4	<0.001	14	3.2 **	36	7.5 **	5	1.1	5	1.0
14. Witnessed atrocities, e.g. mass killings, mutilated bodies	88	20.0	73	15.3	0.083	62	14.1 **	38	8.0 **	1	0.2	4	0.8
15. Been in a combat situation	56	12.7	58	12.2	0.765	16	3.6	16	3.4	10	2.3	10	2.1
16. Any other life threatening or disturbing event	74	16.8	83	17.4	0.860	29	6.6	29	6.1	12	2.7	8	1.7
Summary measure of all traumatic events	323	73.4	399	83.6	0.132	165	37.5	169	35.4	110	25.0	110	23.1

\* $P < 0.05$ ; \*\* $p < 0.005$ ;

A further aim in this study was to investigate associations between psychosocial factors measured in 2011 and exposure to traumatic episodes in the genocide period, with the purpose of exploring whether any indication that those being exposed 17 years earlier fared worse than those not exposed in 1994. Here is a time sequence of 17 years, but as all the data was collected at one point in time and it was considered a cross-sectional study even though it has a retrospective approach related to the genocide period. It was found that people who had experienced traumatic episodes during the genocide period were living under poorer circumstances characterized by lower education, lower incomes and also risked being childless when compared with those who were not exposed to traumatic episodes in that period (Table 5 in paper I). These findings are uncertain as such a long time has elapsed and many other factors could possibly explain such associations besides those investigated.

## 4.2 Associations between traumatic episodes and mental health (Paper II)

The prevalence of mental disorders was considerably higher in women than in men, which is a general finding in most studies irrespective of where and when they are performed. Generalized anxiety disorder (GAD), was the most prevalent condition in both women and men, with prevalence rates being noticeably higher than in other studies.

**Table 4. Prevalence of mental disorders for men and women with p-values for difference N=917.**

Mental disorders	Total population (N=917)		Men (N=440)		Women (N=477)		p-value
	n	%	n	%	n	%	
<b>Major depressive episodes, current (n=915)</b>							
No	736	80.4	386	87.9	350	73.5	<0.001
Yes	179	19.6	53	12.1	126	26.5	
<b>Major depressive episodes, past (n=911)</b>							
No	764	83.9	401	91.6	363	76.7	<0.001
Yes	147	16.1	37	8.4	110	23.3	
<b>Suicidality (n=915)</b>							
No	769	84.0	396	90.4	373	78.2	<0.001
Yes	146	16.0	42	9.6	104	21.8	
<b>Post-traumatic stress disorder (PTSD) (n=913)</b>							
No	789	86.4	407	92.9	382	80.4	<0.001
Yes	124	13.6	31	7.1	93	19.6	
<b>Generalized anxiety disorder (n=913)</b>							
No	580	63.5	292	66.5	288	60.8	0.074
Yes	333	36.5	147	33.3	186	39.2	

### ***Bivariate analyses***

Traumatic episodes experienced during the genocide period were strongly associated with CMD such as depression current and past, suicidality and general anxiety disorders in men (crude analyses). In women, it was observed that traumatic episodes experienced over the lifetime period were more strongly associated with CMD (crude analyses) than traumatic episodes experienced in the genocide period. Women's exposure during genocide period was also associated with suicidality and PTSD (Table 3 in paper II).

### ***Multivariable associations between traumatic episodes and mental disorders***

Among women, *traumatic episodes experienced in the life time* constituted a strong risk factor for MDE current (RR 1.74; 95% CI 1.04-2.65) (Model 1; Table 5), it however lost its statistical significance when spousal physical/sexual violence was added into the model (Model 2; Table 5). Traumatic episodes experienced in the life time was a statistically significant risk factor for MDE past, suicidality and GAD also when other predictors such as assets in the household and physical/sexual partner violence exposure were added (Model 2 Table 5). Influential predictors for a majority of the CMD investigated, were lack of assets (used as a proxy for poverty), exposure to physical/sexual partner violence while poor social support was associated with GAD only. All analyses were controlled for age.



**Table 5. Associations between traumatic episodes experienced over life time and mental disorders in women, presented as crude and adjusted relative risk (RR) with their 95% confidence intervals. N= 477.**

	Major depressive episode current				Major depressive episode past			
	n %	Crude	Model 1*	Model 2**	n %	Crude	Model 1*	Model 2**
<b>Traumatic episodes life time</b>								
0 episode	13 (16.7)	1	1	1	13 (16.7)	1	1	1
≥1 episodes	113(28.4)	1.70 (1.04 – 2.57)	1.74 (1.04 – 2.65)	1.66 (0.98 – 2.57)	97 (24.6)	1.47 (0.88 – 2.29)	1.52 (0.89 – 2.38)	1.45 (0.84 – 2.31)
<b>Assets in the household</b>								
At least one of the items	69 (20.9)	1	1	1	61 (18.7)	1	1	1
None of the items	57 (39.0)	1.87 (1.41 – 2.37)	1.84 (1.38 – 2.35)	1.70 (1.24 – 2.22)	49 (33.6)	1.80 (1.32 – 2.36)	1.79 (1.30 – 2.35)	1.66 (1.19 – 2.23)
<b>Physical/sexual violence exposure life time</b>								
No	69 (19.7)	1	1	1	63 (18.1)	1	1	1
Yes	57 (45.6)	2.32 (1.78 – 2.87)	-	2.27 (1.73 – 2.85)	47 (37.6)	2.08 (1.53 – 2.69)	-	1.91(1.38 – 2.53)
<b>Social support</b>		na	na	na		na	na	na
Good social support								
Poor social support								
	Suicidality				General anxiety disorder			
	n %	Crude	Model 1*	Model 2**	n%	Crude	Model 1*	Model 2**
<b>Traumatic episodes life time</b>								
0 episode	9 (11.5)	1	1	1	23 (29.5)	1	1	1
≥1 episodes	95 (23.8)	2.06 (1.13 – 3.42)	1.98 (1.08 – 3.30)	1.91 (1.03 – 3.22)	163(41.2)	1.39 (0.99 – 1.84)	1.89 (1.34 – 2.40)	1.90 (1.34 – 2.42)
<b>Assets in the household</b>								
At least one of the items	66 (19.9)	1	1	1	119(36.3)	1	1	1
None of the items	38 (26.0)	1.31 (0.91 – 1.79)	1.33 (0.93 – 1.83)	1.22 (0.83 – 1.71)	69 (45.9)	1.26 (1.00 – 1.54)	1.20 (0.91 – 1.49)	1.10 (1.82 – 1.41)
<b>Physical/sexual violence exposure life time</b>								
No	62 (17.6)	1	1	1	117(33.4)	1	1	1
Yes	42 (33.6)	1.91 (1.37 – 2.53)	-	1.86 (1.32 – 2.49)	69 (55.6)	1.67 (1.36 – 1.96)	-	1.64 (1.30 – 1.97)
<b>Social support</b>		na	na	na				
Good social support					97 (33.4)	1	1	1
Poor social support					70 (49.0)	1.46 (1.16 – 1.77)	1.57 (1.24 – 1.89)	1.61 (1.28 – 1.94)

\* Model 1 adjusted for age, \*\* Model 2 added physical/sexual violence exposure to the model

Among men, traumatic episodes experienced during the *genocide period* was a statistically significant predictor of all mental disorders under consideration, apart from PTSD in multivariable logistic regression analyses (Table 6). In addition, lack of assets/poverty was associated with all mental disorders apart from suicide risk in men (Table 6). However, regression

Traumatic episodes related to the genocide period, mental health effects and perceived barriers to care facing young adults in Rwanda

analysis for *life time episodes*, including age and few assets in the household as the latter proved to be a strong predictor, showed statistical significance only with general anxiety disorder (GAD) (RR 1.65; 95% CI 1.22-2.09) (not presented in table).

**Table 6. Associations between traumatic episodes experienced during genocide period and mental conditions in men, presented as crude and age adjusted relative risk (RR) with their 95% confidence intervals. N=440.**

Variables	Major depressive episode current			Major depressive episode past		
Men (N=440)	n%	Crude RR	Adjusted RR*	n%	Crude RR	Adjusted RR*
<b>Traumatic episodes genocide period</b>						
0 episode	25 (9.1)	1	1	13 (4.7)	1	1
≥1 episodes	28(17.0)	1.86 (1.13 - 2.93)	1.80 (1.08 - 2.86)	24(14.6)	3.09 (1.65 - 5.44)	3.02 (1.59 - 5.37)
<b>Assets in the household</b>						
At least one of the items	31 (9.6)	1	1	21 (6.5)	1	1
None of the items	22(18.8)	1.95 (1.18 - 3.07)	1.92 (1.15 - 3.04)	16(13.7)	2.09 (1.13 - 3.67)	2.04 (1.08 - 3.63)
Variables	Suicide risk			Generalized anxiety disorder		
Men (N=440)	n%	Crude RR	Adjusted RR*	n%	Crude RR	Adjusted RR*
<b>Traumatic episodes genocide period</b>						
0 episode	19 (7.0)	1	1	77(28.1)	1	1
≥1 episodes	23(13.9)	2.01 (1.13 - 3.38)	2.15 (1.21- 3.64)	70(42.4)	1.51 (1.17 -1.87)	1.51 (1.16 - 1.87)
<b>Assets in the household</b>						
At least one of the items	32 (9.6)	1	1	98(30.4)	1	1
None of the items	16(13.7)	1.67 (0.94 - 2.82)	1.77(0.99 -3.00)	49(41.9)	1.38 (1.04 -1.37)	1.37 (1.03 - 1.73)

From the two population based studies on traumatic episodes and mental health it can be concluded that men and women were both exposed to traumatic episodes in the 1994 genocide and both men and women suffered from mental disorders in 2011, i.e. at the time of the data collection. As the

traumatic episodes experienced in the genocide period kept its statistical significance even when other strong predictors were entered, a cautious conclusion is that the mental problems experienced in 2011 to a certain degree were a consequence of a trauma experienced 17 years earlier.

Even the youngest age group reported such incidents but it is not possible in this study, to establish whether they really experienced such episodes or remember them as they have been told and heard about them ever since. Considering that the youngest were only three years of age in 1994, it might be an inter-generational effect. Moreover, the yearly commemoration ceremonies in the country to honour the deceased and not allow memories to fade, make these episodes come alive even for those who were very young at the time.

Additionally, for women it was noted that partner physical/sexual violence, ongoing or earlier experience, was highly associated with all mental disorders investigated. When trying the two strong risk factors for mental disorders, i.e. partner physical/sexual violence and traumatic episodes lifetime in the same analysis, both kept their statistical significance. Evidently, women were plagued by ongoing or more recent trauma but also of what had happened in the past, and it might be that such traumatic experiences also interact.

### **4.3 Mental disorders and barriers to care (Paper III)**

The study participants consisted of 20 males and 23 females of which 28 were trained in mental health; two were psychiatrists, 20 were mental health nurses, six were clinical psychologist with two years of training, and 15 were nurses without any mental health education but with practical experience of seeing people with mental health problems, and one of those was trained in gender based violence. A psychosocial center is an out-patient clinic aimed for people with mental and social problems, staffed with medical doctors/psychiatrist, mental health nurses and clinical psychologists.

**Table 7. Characteristics of the study participants. N=43.**

FGD*	Setting	Number of participants and sex distribution (Male:Females)	Age (years) Mean (Min-Max)	Number of participants with specialized training in mental health	Profession
1	Mental hospital	10 (7:3)	36.6 (29-50)	10	Psychiatrist (1) Mental health nurses (8) Clinical psychologist (1)
2	District hospital	7 (1:6)	32.4 (26 – 38)	2	Mental health nurse (1) Clinical psychologist (1) General nurses (5)
3	Mental health center	7 (4:3)	32.0 (27 – 46)	7	Psychiatrist (1) Mental health nurse (4) Clinical psychologist (2)
4	District hospital	7 (4:3)	38.1 (28 – 59)	1	General nurses (5) Mental health nurse (1) General nurse for gender based violence (1)
5	Psychosocial center	6 (3:3)	32.5 (26 – 40)	6	Mental health nurses (5) Clinical psychologists(1)
6	District hospital	6 (1:5)	32.0 (27 – 44)	2	Mental health nurse (1) General nurses (4) Clinical psychologist (1)
<b>Total</b>		43 (20:23)	34.2 (26 -59)	28	

\* FGD; Focus group discussion

The emerging theme was “*A constant struggle to receive appropriate mental health care for mental disorders*”. The participants expressed a number of barriers and only few facilitating factors that people experienced when seeking mental health care services. The theme emerged from two main categories namely, “*People facing numerous barriers when seeking health care for mental disorders*” and “*The use of scarce facilitators to enable health seeking for mental disorders*”. These two categories emerged from eight subcategories, of which six described barriers to mental health care seeking and two described facilitators to mental health care seeking.

**Table 8. An overview of the theme, categories and their sub-categories**

Sub-category	Category	theme
Poverty and lack of family support	People facing numerous barriers when seeking health care for mental disorders	A constant struggle to receive health care for mental disorders
Fear of stigmatization		
Poor community awareness of mental disorders		
Societal beliefs in traditional healers and prayers		
Scarce resources in mental health care		
Gender imbalance in care seeking behaviour		
Collaboration between authorities and organisations in mental health	The use of scarce facilitators to enable health seeking for mental disorders.	
Family with awareness of mental disorders and health insurance		

***“People facing numerous barriers when seeking health care for mental disorders”***

We found that the health care professionals pointed at poverty, lack of support and fear of stigma as main barriers to mental health care. The health care professionals had as well observed clear gender differences in the care seeking process. For example, women were perceived as more willing to adhere to treatment appointments while men tried to solve their mental problems on their own, while sometimes resorting to drugs and alcohol abuse. The health care professionals further identified scarce resources committed to mental health, resulting in poor access and quality of care and poor community awareness of mental disorders as major barriers to mental health care.

***“The use of scarce facilitators to enable health seeking for mental disorders”***

Few facilitating factors were brought up by the health care professionals, however, observed that having a supportive family with awareness of mental disorders and/or embraced by a health insurance scheme made a critical difference for the person suffering from a mental condition. The other

facilitating factor was collaborating with other organisations, such as the police, as they occasionally find persons with mental conditions left without any support walking the streets, and bring them to health care services. A more detailed description of the findings is presented in paper III.

## 4.4 Gender differences in care seeking for mental disorders (Paper IV)

In this study the participants were the same as described in paper III. The emerging theme in this study was *“Prevailing gender norms and stigma negatively influence marital stability and access to mental health care for men and women with mental disorders”*.

**Table 9. An overview of sub-categories, categories and theme**

Sub-categories	Categories	Theme
Sensitive women are in need of care	Differing societal expectations on health care seeking behaviour in men and women with mental disorders	Prevailing gender norms and stigma negatively influence marital stability and access to mental health care for men and women with mental disorders
Strong men are capable to manage themselves		
Women are adherent to the recommended care	Gender differences in perceptions of mental disorders influence how counselling and treatment are received	influence marital stability and access to mental health care for men and women with mental disorders
Men are reluctant to accept mental health counselling and treatment		
Opposite gender of health care professionals and patients cause problems in counselling		
Women with mental disorders risk being rejected by spouse and family members	Gender stereotypes and stigma attached to mental disorders bring consequences for the relationships	
Men with mental disorders are often supported by their spouse		

Our findings indicate that strong gender norms related to care seeking behaviour and stigma attached to mental health negatively affect the possibilities of accessing quality care when suffering from a mental disorder and also influence men’s and women’s marital relationships differently. The theme suggests that men are disadvantaged by avoiding care seeking due to stigma and strong masculinity norms but favoured by the support offered by their wife as part of her duties in family life, also related to masculinity norms. Women were disadvantaged as in many cases women with mental disorders were not accepted by the husbands and divorce was a potential outcome.

***Differing societal expectations on health care seeking behaviour in men and women with mental disorders***

The participants expressed that society expects men to be strong when faced with a mental disorder and able to deal with it by themselves, while women are expected to seek health care as they are considered as sensitive and not able to take care of the problem themselves. Hence different societal expectations of behaviour in men and women resulted in women commonly seeking care more often than men when suffering from a mental problem.

***Gender differences in perceptions of mental disorders influence how counselling and treatment are received***

Participants stressed that gender is of importance in counselling and treatment of mental disorders as women would easily accept the proposed treatment, but men were perceived as reluctant to accept mental health care and none adherent to counselling.

***Gender stereotypes and stigma attached to mental disorders bring consequences for the relationships***

Cultural views of mental disorders were expressed as having a differing impact on men's and women's relationships. It was perceived that women with mental disorders were being rejected in the relationship by their partners or boyfriends while men were being supported by their spouses who might, for example fetch medication for their partners from the health facility.

## **5 DISCUSSION**

### **5.1 Main findings**

#### ***Prevalence of traumatic episodes experienced during the genocide period, during lifetime and in the past three years***

Women were to a higher extent exposed to traumatic episodes than men during their lifetime period. During the genocide period almost equal proportions of men/boys and women/girls reported experience of such trauma. The most commonly occurring episodes reported by both men and women for life time and exposure and during the genocide period were '*Experienced imprisonment of a close family member*', '*Experienced a murder or unnatural death of a family member or a friend*', '*Been a refugee, forced to flee from home to escape danger/persecution*' and '*Witnessed atrocities, e.g. mass killings, mutilated bodies*'. Men and women exposed to traumatic episodes during the genocide were 17 years later at a higher risk of living in poorer circumstances than those not directly exposed to traumatic episodes in this period.

During the past three year period (2009-2011), traumatic episodes were reported by men and women to a similar extent; the most commonly reported episodes were '*Experienced imprisonment of close family member*' and '*Witnessed a traumatic event to a loved one*' and quite a few men reported '*Imprisonment, kidnapped, held captive*', the underlying reason for this needs further investigation. (Paper I)

#### ***Traumatic episodes and their association with mental disorders***

Of the mental disorders investigated, i.e. depression, PTSD, suicidality and GAD, women were for the majority of conditions twice as often affected as men. Traumatic episodes experienced during the genocide and during lifetime period contributed to current mental health status in men and women. However, among women, exposure to physical/sexual partner violence was also strongly associated with all mental disorders under investigation as was poverty in terms of lack of assets in the household for men and women.

#### ***Health care professionals acquired experiences of barriers and facilitators' that people with mental disorders face***



The theme that emerged “*A constant struggle to receive mental health care for mental disorders*” comprised a number of barriers and few facilitators at individual, family, community and structural levels that people faced when seeking mental health care services. Barriers identified by health care professionals working in mental health services included poverty and lack of family support, fear of stigmatization, poor community awareness of mental disorders and beliefs in traditional healers and prayers. Furthermore, at a structural level, scarce resources for mental health were identified alongside a gender imbalance in care seeking behaviour. Having a supportive family with awareness about mental disorders and being enrolled in a health insurance scheme were perceived as critically important for successful treatment of a mental disorder.

Health care professionals’ view of barriers was based on their knowledge, experience, perceptions and understanding of important barriers at structural and individual levels (Paper III) but as they have grown up and live in the same culture, this possibly also affects their statements.

***Strong gender norms and stigma affect marital stability and access to mental health care services***

The theme was “*prevailing gender norms and stigma negatively influence marital stability and access to mental health care for men and women with mental disorders*”.

It became evident that health care professionals had observed clear gender differences in terms of how men and women seek health care. They explained the differing societal expectations on health care seeking behaviour in men and women with mental disorders that is prevailing in the country. Women were expressed as “weak” that seek help and men as “strong” that solve problems on their own, when faced with mental disorder. In addition, it was stated by the health care professionals that gender differences in perceptions of mental disorders influence how counselling and treatment are received. Women were perceived as adherent to the recommended care while men were perceived as reluctant to accept mental health counselling and treatment.

Gender stereotypes and stigma attached to mental disorders were perceived as things that negatively affect the relationships. According to health care professionals, women with mental disorders risk being rejected by spouse and family members while men with mental disorders often are supported by their spouse.

## 5.2 Our findings in relation to other studies

The prevalence of experienced traumatic episodes varies in the few studies performed on this issue in Rwanda; one study performed ten years after the 1994 genocide shows higher prevalence of different traumas but in their study the age group was 18-94 with a median age of 36 years, as compared to our study where a younger age group was investigated, i.e. 20-35 years (32). Other studies have investigated the mental health status in the Rwandan population since the genocide in 1994 and they unanimously find comparatively high prevalence of mental disorders. A study conducted five years after the genocide (368 men and women, mean age 35.7 years) shows that the rate of depression was 11% in men and 17% in women, which is somewhat lower than in our study (35). Fourteen years after the genocide, a study on PTSD and MDE was conducted on 962 people, aged 16–34 years, using the MINI instrument, which was also used in our study (37). Overall prevalence of PTSD was 26%, (women 21%; men 30%), while MDE in the total sample was 23%. These figures are similar to ours, apart from PTSD in men, which was considerably lower in our study (7.1%). The conclusion was that mental ill health is still prevalent in the Rwandan population (37).

Available studies that investigated mental health in Rwanda, all point at high prevalence of mainly depression and PTSD in both men and women. Most studies included one traumatic episode commonly occurring during the genocide period as a possible risk factor.

There are however several other reasons to be taken into account as contributing to common mental disorders. Other studies find poverty as an additional factor of importance and so is women's exposure to physical, psychological as well as sexual intimate partner violence (35, 36, 46). However, no other study than ours investigated intimate partner violence against women over the life time, poverty and exposure to genocide trauma in the same analysis. It was demonstrated that all three variables contributed to mental disorders years after the genocide. Few men are exposed to intimate partner violence in Rwanda (45), but poverty was a risk factor also for mental ill-health in men.

Poverty disempowers people, especially women although also men, and it increases their social isolation, hereby exposing women to more psychological stress (8, 21, 202). Prolonged conflicts in a country have shown to increase poverty levels, worsen socio-economic conditions and

exert negative influence on mental health outcomes of the citizens (17, 22, 23).

Women in general, in low as well as in high income countries, report higher levels of mental ill-health than men (202-204), and this has been ascribed to the inferior position in society manifested in various ways.

Women who have experienced an internal conflict are affected not only by the trauma to herself and her family, but also by the lifelong damage of their reputation and the stigma following rape (165). A study conducted in Zimbabwe, investigating risk factors for CMD among primary health attenders, found that female gender is associated with CMD, economic deprivation and distress and disability (166).

In conclusion, the findings from various studies including this study, is that the prevalence of mental disorders is high in Rwanda compared to what is seen in other low-income countries. Many factors contribute to this, of which the trauma that happened during the genocide seems to be an important one, but other strong factors contribute, such as poverty and partner violence against women.

In the two qualitative studies, barriers to mental health services were discussed with health care professionals with experience of encountering men and women with mental problems. Several barriers to mental health care services were identified related to the structural as well as the individual level. A mental disorder is a stigmatizing disease, being both a structural level and an individual level issue. Certain diseases, such as HIV, mental disorders and tuberculosis carry such stigma, which is fostered at societal level, which could lead individuals affected by such a disease to avoid seeking health care in order to not reveal suffering from it and to protect family members from such “disgrace”. Further factors to overcome were the poor awareness of mental disorders at community level and the community’s strong beliefs in healers and prayers, which contributed to further delays in help seeking.

The only earlier study available from Rwanda on barriers to mental health services, carried out on a population representative sample, emanates from our research programme (154). This study included men and women suffering from either depression or suicidal thoughts. The identified barriers were mainly related to accessibility (no transport available, too expensive, no health insurance) and acceptability of health services (do not trust to get

correct treatment, do not know where to turn, do not believe treatment would help).

Other studies report on barriers to antenatal care services, or primary care services and commonly two major factors were of importance to reduce such barriers. These were to improve service delivery and to reduce financial barriers (86, 205, 206). A review study involving five countries, including Rwanda, found that non-financial barriers were ethnicity, religion, physical accessibility, decision-making, gender and autonomy, and finally knowledge, information and education (207). Their analysis highlighted that non-financial factors are influential access barriers, of which many relate to the acceptability dimension of the Right to Health concept (121). Some of these findings are similar to what was found in our two qualitative studies on barriers to care.

In addition, although there are no studies from Rwanda on people with mental problems who seek help from traditional healers, there is a study showing that 37 % of women with breast cancer sought care from traditional healers (208). Visiting a traditional healer and prayers were discussed also in our study as actions taken before visiting health care services, hereby delaying proper health care seeking and treatment. This is possibly due to many factors such as the stigma attached to the disease, but also structural factors such as distance to the health care unit and not knowing where to turn (154).

A study conducted on gender differences in ten countries, including more than 37.000 participants, shows that at least nine of the participating countries were in agreement with our finding that women more often seek mental health care than men (209). But one study disagrees and reports that in case of severe mental disorder, men are more likely than women to use the mental health care services (210). The hesitance of men from using mental health care services is influenced by strong cultural expectations of fulfilling the traditional masculinity role (211, 212).

## **5.3 Methodological considerations**

### ***The quantitative study***

Participants to be included in the population based study were selected randomly with support from Statistics Rwanda, who provided lists of villages in the Southern Province with number of inhabitants and then made a random

selection in accordance with instructions given. There is no reason to believe a random error was made or any systematic error, in the selection process. In the villages a systematic way of selecting households for inclusion was worked out and applied in all villages.

Face to face interviews were conducted by clinical psychologists with two years of professional training, and who were experienced in collecting data through interviews as they belonged to a team of interviewers at University of Rwanda. A response rate of 99.8% was obtained, which is similar to other national surveys of the country (60, 82). Such a high response rate was possible due to many reasons, one being that the majority of the population (80%) live in rural areas and work in the informal sector like agriculture. Hence, they were easily accessible either in their household or on their farm. Furthermore, interviewers and respondents were of the same sex and age range, which had a positive influence on quality and accuracy of the data collected (213).

Another strength was the use of validated tools. The Harvard Trauma Questionnaire has been used in several Sub-Saharan studies in countries with post conflict history (188), but only Part I was used as in our study and the more refined parts of the HTQ were not used. Examples of trauma experienced in the genocide period were inquired about and then just summed into an exposure variable.

The Mini International Neuropsychiatric Interview, MINI, is a validated instrument commonly used and referred to as a diagnostic tool, used to assess mental disorders (214). It is however a screening instrument that preferably should be complemented by individual interviewing for an accurate diagnosis, but its sensitivity and specificity has recently been assessed for diagnosing depression in comparison with other similar instrument and was found to meet criteria for adequate sensitivity and specificity (192).

In addition, quantitative and qualitative methods were used. All data in the quantitative studies were sex disaggregated. A variable for intimate partner violence (IPV) was included in multivariable logistic regression analyses, which showed that IPV was independently associated with mental disorders.

There are however issues to be considered. Our participants were as young as 3-18 years during the genocide period. Those who were three to five years in that period may have only scattered memories and may potentially forget what happened to them at such an early stage in their life, and may underreport traumatic episodes. Similarly participants were asked about age

at event, which might be difficult to accurately respond to due to recall bias and memory repression. In addition, over estimation of traumatic episodes might have happened as a result of inquiring about age at time of traumatic episodes and subsequent formation of  $1994 \pm 1$  year variable that was formed by all events that occurred between 1993 – 1995 periods. However, after applying this method, we found that the prevalence of traumatic episode in our study concurs with another study from Rwanda (215).

Our study is considered to be of a cross-sectional design, as all data were collected at one point in time. It could however be argued that it is a retrospective cohort study considering the genocide period, but an objection is that no data has been collected from any earlier period. Therefore, the attempt to investigate differences in current life circumstances between exposed and non-exposed may be subject to confounding. Conclusions on causal relationships should be drawn with cautiousness from these studies even though there is a clear time difference between exposure and outcome.

When comparing our estimates for the common mental disorders assessed, the prevalence of general anxiety disorder came out as particularly high in this study. This may be explained by the fact that MINI instrument is not fully able to discriminate between GAD and PTSD, as PTSD presented with a rather low prevalence in comparison with findings from other studies performed in Rwanda and elsewhere. However, it might also be that general anxiety disorder was not fully understood by the interviewers but interpreted as anxiety in general and in this way became overestimated.

Assets in the household was used as a proxy for poverty, and this method has been used in other national surveys of Rwanda to measure poverty levels because most of the people do work within the informal sector with no formal employment or a fixed salary. A housing standard variable was tried but found not to discriminate between households while a variable constructed out of nine assets that may be available in the household did, and this summary variable worked well as a discriminatory variable, then used as a proxy for socio-economic status.

As Rwanda is a small country with 12 million people, generalization of our results from the epidemiological studies to the entire country can be done as our sample mirrored the urban/rural proportions of inhabitants and generally their life circumstances are similar in urban and rural areas respectively.

### ***The qualitative study***

The strengths of the qualitative studies were the purposive selection of participants from different levels in the health care system and from different locations. The participants represented various professions, men and women, from rural and urban areas. It was decided to select health care professionals as the informants and not people suffering from a mental condition to get an aggregated understanding of barriers to mental health care. The possibility of interviewing persons with mental disorders individually was discussed but abandoned due to difficulties in finding those who would be willing to speak and for safety reasons.

The majority of the informants were nurses (35/43), well acquainted with people's life circumstances and the scarce resources allocated to mental health as they encounter and treat the majority of mental cases. *Credibility* was ensured by the purposive selection of informants from the mental health units available in the country, apart from the national mental health hospital, and from district hospitals similar to other such hospitals in the country. There was sufficient time with participants (90 minutes) so as to engage them and capture their multiple realities, to ensure credibility of the studies (182). Two of the authors with different cultural background and professional experience (LR and MP) analyzed the material and discussed the findings throughout the analysis phase. Finally results were discussed and agreed upon by all co-authors of which three were medical doctors, specialized in different fields of medicine but experienced in content analysis. Back translation was done to cross-check the original text to ensure authenticity.

Whether the findings can be generalized to the entire country (*transferability*) can be discussed. As the informants represented almost all of the mental health units in the country and district hospitals are similarly staffed all over the country, the informants had different professional backgrounds and hereby had dissimilar experiences. Further, life circumstances in the population are similar in the four provinces. We believe our findings shed light on several aspects of the area under study and can be generalized to the country. The gendered and aspects of health seeking behaviour that were discussed by the informants were traditional and possibly influenced by the prevailing culture. We have however, no reason to believe this is not a general view in the country. To improve *dependability*, data was collected with local researchers familiar with local context and the study tool took into account all social contexts to ensure capturing all necessary aspects of the problem under study. For *confirmability* purposes, the transcripts were read several times and by more than one researcher (179). We also compared our different views of the data at hand (to triangulate results), and obtained areas

of convergence after discussions (216). By doing so, we ensured that conclusion about research findings were anchored in the data for the purpose of neutrality in relation to researchers' preconceptions (182).



## 6 CONCLUSION

The prevalence of mental disorders in men and women in Rwanda is comparatively high and higher in women than in men partly due to partner violence and trauma experienced during the genocide period but also after this period and currently. People suffering from a mental disorder in Rwanda face several barriers to efficient care and this is possibly part of the explanation to why prevalence rates of common mental disorders are comparatively high. Our study reveals a number of barriers that need interventions at societal, community and individual level alongside initiatives to reduce the stigma attached to mental disorders. Furthermore, individuals need to be better informed about mental disorders, how they can be treated and where to get such treatment, i.e mental health literacy needs to be improved.

This demands effective and high quality mental health services which are accessible, affordable and appropriate to people's needs. Preventive and curative interventions should be established in parallel. To overcome the challenges of limited resources committed to mental health, a positive shift for prioritization of mental health care will be required to enable more supportive mental health care infrastructures that match with the prevailing burden of mental disease in the country. Decentralization of mental health services to the primary health care level, as suggested by WHO, is discussed in Rwanda and would improve early detection and efficient treatment by motivated and trained nurses and clinical psychologists. Psychiatrists are needed in Rwanda as well as psychotherapists.

Efforts to address the burden of CMD in Rwanda need to target determinants of poverty and social deprivation and poor social support in general, as well as violence against women in the family. A mental health literacy campaign should be launched nationwide to reduce mental illness related stigma and raise awareness of when and where to seek mental health care.

The current gender norms exert a strong influence on mental health care seeking and treatment outcomes. Gender inequality affects both men and women and neither men nor women will have appropriate care when such norms remain strong. Educational interventions to address the stigma attached to mental illness and gender inequality is a necessity to address the norms that limit men and women from utilizing the limited, but available mental health services.

Overall, it is the government's responsibility to provide health care services through its established health system that are accessible, available, and acceptable to all and of good quality. In Rwanda, a mental health policy is in place and steps are taken to improve mental health services by aiming for its integration into primary health care services.

## 7 FUTURE PERSPECTIVES

### 7.1 Mental Health policy implications

The Ministry of Health of Rwanda adopted a mental health policy that identifies a number of areas that are critical for improving delivery of quality mental health care. They include among others, to integrate mental health care to the lowest level of care (i.e. primary health centre level). In addition, the policy also aims to promote community involvement in the promotion and care of mental health as well promoting sectoral collaboration.

Of importance is to raise awareness in society of mental disorders to combat mental health illiteracy and reduce stigma. This need information campaigns to the people through local media and educational activities directed at professionals within the health care services.

It is vital to accelerate decentralization of mental health care services by integrating it into the primary health care system (health centers), as this would considerably improve accessibility. While there is ongoing training of mental health personnel, the currently available numbers of psychiatrists, mental nurses and clinical psychologists is far less in relation to the magnitude of the mental problems at hand, so an increase in numbers of such professionals is urgently needed especially if and when the planned decentralisation is to materialise. Both men and women should be granted access to a trained professional in mental health when suffering from such a condition.

To improve the locally available and affordable interventions, community health workers form a valuable asset at the village level in educating and informing its people on health matters. Community health workers with basic training in mental health could sensitize the people in villages to become aware of mental illnesses and hereby fight the stigma and discrimination related to mental ill-health. Such activities would help and support people with mental problems to seek health care services instead of visiting traditional healers and churches when faced with a mental problem.

At individual and family level, knowledge and understanding of mental disorders to allow enough support to people with mental problems is crucial and calls for information and educational activities. Health insurance coverage is already quite high but could still be improved among people with mental problems to facilitate access to mental health care services.

A contributing reason for women suffering more from common mental disorders than men is gender inequality in terms of women's lower decision-making capacity, lower access to higher education and to paid employment, exposure to partner violence as well as to how domestic chores are shared between family members. There are already efforts to improve gender equality in the country, but mental illness among women remains high and such efforts need to continue so as to achieve a higher level of gender equality in a longer perspective.

## **7.2 Research Implications**

Traumatic episodes were reported in the past three years, 17 years after genocide. It was not evident why and this requires further research.

Mental disorders, health care seeking patterns and perceived barriers to care need more attention in research. Studies are needed to investigate in more detail the reasons for women's mental ill-health and partner violence should be taken into consideration alongside other important possible determinants. As the current research on barriers to care focused on health care professionals' perspectives, interviews with individuals, both men and women, with experience of mental illness themselves would benefit the further understanding of barriers to care when suffering from a mental condition. Furthermore, family members of people with mental illnesses can also bridge the knowledge gap related to barriers to mental health care.

## 8 ACKNOWLEDGEMENT

This research was made possible by a grant through the Cooperation between the Swedish International Development cooperation Agency (SIDA) and the University of Rwanda. The funding is very much appreciated.

Special thanks to the Rwandan men and women who entrusted us with their information that enabled this study. Without your information this study would have been impossible. Sincere thanks to the data collectors, who worked tirelessly to collect good quality data.

To my research mentors and supervisors.

**Gunilla Krantz**, Through this journey, I was fortunate to meet the right persons at the right time. I appreciate the tenacity and generous hospitality accorded me when I first visited Gothenburg. The overview of my PhD journey sessions we discussed from the onset multiplied my vigor, zeal and enthusiasm. Thank you that throughout this journey you have shared your knowledge, research skills and words of encouragement not to despair. I have benefited from your conscientious research and it has been indispensable. You have always been concerned about my welfare and I have learned a holistic package from you as good supervisor.

**Mogren Ingrid**, I would like to thank you for your attention to details, the SPSS sessions specifically the usage of syntax, and your timely review and feedback to all my manuscripts was superb and re-energizing. I appreciate so much the notes from the half-control seminar, such were very useful to prepare for the final PhD defense.

**Joseph Ntaganira**, My local supervisor, the discussion session we had at the beginning were influential to my decisions making process to take on my PhD journey. The guidance I had from you throughout this four year's journey was remarkable.

**Persson Margareta**, you have been very instrumental throughout my qualitative papers. Your timely and reflectional comments have built my qualitative research skills. I will forever cherish your simplicity and down-to-earth approach.

To all my half-time control board members; Fredrik Spak, Margda Waern and Anna Dencker. Your assessment and comments during my halftime

control seminar was helpful for areas of further reflection and improving my research work.

**Christopher Pickering**, thank you for your efforts to edit my manuscripts and timely feedbacks, it was such an essential contribution to all my manuscripts.

**Gunnel Hensing**, thank you for hosting me in the department that you head. I appreciate all your time to host us at your home located on an island, it's memorable.

**Kakoma Jean Baptiste**, I am so thankful for all your administrative support to my studies abroad during your tenure as Dean of SPH.

**Jeanine Condo**, Your support throughout this PhD journey was instrumental. Your proactive administrative support even on weekends when I had to travel out of the country was remarkable. I learned from your leadership qualities. I want to thank you for being there for me when I needed you most. May the almighty guide you in your new assignment.

**Paulin Basinga**, Through your efforts and leadership, the CDC grant/ Project was awarded to our institution. This grant has taken care of my travels and subsistence stay in Gothenburg. Countless appreciation to you and the team you led during writing the grant. Also special thanks to SPH leadership who took over the mantle after your departure and spearheaded the project to completion.

**Robin Fornazar**, you are the second person I knew after my supervisor in the department. Since that time you have been friendly and very helpful to me as an alien in Sweden. Sorry that sometimes I bothered you a lot especially when I wanted to buy online air tickets. I am grateful to you and **Frida Silfversparre**, both of you designed the SPSS template for our data.

To all members of the department, **Jesper Löve**, **Solveig Lövestad**, **Matilda Eriksson**, **Helen Carlsten** and many others, I am thankful to all your support in one way or the other. **Jeannette Nyirahabimana**, I appreciate enormously that you always gave a timely consideration of my travel arrangements and all the prerequisites that goes with it.

**Fr. Emmanuel Ruvugwaho**, Ever since we met in March 1987 as a little boy, your influence on my education expedition has been a resounding treasure. Your unwavering belief in me even when there seemed no reason to

believe. I will forever cherish your impact on my life. An enormous amount of gratitude to all my meticulous brothers (RIP) and sisters for their invaluable conscientious

My family and friends who have supported me through this journey, Lady Daphine Kanyana, my wife and mother of our children, I am proud of your understanding and resilience that has tolerated several months of my absence. I am grateful that you took full responsibility and management of our home. I pride in you. To Blessing and Ivan, I know you longed for my full presence at home but it was absolutely necessary for me to travel to Sweden. I owe you a great debt of gratitude for your understanding, at least in future if not now.

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