UNIVERSITY of RWANDA

THE SCREENING OF DEPRESSION AMONG ADOLESCENTS WITH CHRONIC DISEASES AT THE UNIVERSITY TEACHING HOSPITAL OF KIGALI, RWANDA

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Masters of Medicine in Pediatrics

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By

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Declaration

I declare that this Dissertation contains my original work except where specifically acknowledged

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Abstract

Background

The burden of chronic diseases is increasing worldwide, mainly among children and adolescents (1,2). Depression significantly impairs the quality of life and contributes to increasing the burden of chronic disease in adolescents. (3–7). In order to improve the outcome of adolescents with chronic diseases comprehensive care, including early detection of depression must be established. The objective of this study was to determine the prevalence and severity of depression among adolescents with chronic diseases attending a tertiary hospital clinic in Rwanda, as well as to describe the socio-demographic factors associated with depression.

Methods

This was a cross-sectional study, done at Centre d'Excellence Mpore (Pediatric outpatient clinic) of CHUK; a modified PHQ-9 for adolescent was used as a screening tool for depression among adolescents enrolled in chronic disease outpatient care. Obtained data were entered and analyzed using SPSS version 20.

Results

We found the prevalence of depression in 23.2 % of the 142 adolescents enrolled in our study. Among them, 1.4% have severe depression, 6.3% have moderately severe depression, and 15.5% moderate depression. We found evidence of an association between being in non-boarding schools and having positive depression (p-value: 0.019). However, we were unable to find any association among other socio-demographic factors and depression as our sample size was not powered enough to detect that association.

Conclusion

Depression rates being high among adolescents with chronic diseases is a big challenge. The integration of mental health in their management is paramount. A tool like modified PHQ-9 for adolescents can be used for early detection of depression among adolescents with chronic diseases even in primary health care settings. Further studies are needed to look more in associated factors with depression as our sample was not powered enough to detect theses differences. It would also be interesting to know rates of depression in adolescents with non-chronic diseases, adolescents in schools and in general adolescents' population.

Keywords

Depression, Chronic disease, Screening, Adolescent

List of Symbols and acronyms

AAP	American Academy of Pediatrics
APA	American Psychiatric Association
BDI	Beck Depression Inventory
CDI	Children depression inventory
CBHI	Community Based Health Insurance
CEM	Centre d'Excellence Mpore (Pediatric outpatient clinic)
CHUK	Centre Hospitalier Universitaire de Kigali/University Teaching Hospital of Kigali
CMHS	College of Medicine and Health Sciences
DSM4	Diagnostic and Statistical Manual for the mental disorders 4th edition
DSM5	Diagnostic and Statistical Manual for the mental disorders 5th edition
HRH	Human Resources for Health
ID	Patient Identification number
IRB	Institution Review Board
PHQ-9	Patient Health Questionnaire, 9 items
RSSB	Rwanda Social Security Board
SPSS	Statistical Packages for Social Sciences
UR	University of Rwanda
US	United States
WHO	World Health Organization

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Background (literature review)

Introduction

Chronic diseases, defined as diseases lasting for 3 months or longer. According to the WHO 2002 World Report, Chronic diseases are the leading cause of mortality and morbidity (1,8,9). There is a significant increase in the burden causes by these chronic diseases in the pediatric population, especially in low and middle-income countries (10–12). Rwanda, as well as other low and middle-income countries, has experienced a significant rise in chronic disease burden in childhood and adolescence (3,5).

Depression according to the WHO and DSM 5 is defined as a persistent feeling of sadness, hopelessness, and loss of interest in activities that people used to enjoy lasting for 2 weeks or more. Apart from emotional symptoms, depression also presents with associated physical symptoms (i.e. headache, chronic pain, and digestive symptoms) (13).

Literature search description

A literature review was performed to identify research on depression screening in adolescents. Pubmed was searched using the terms outlined in Appendix 1. This resulted in 260 articles. The abstract of these articles were searched and only 30 relevant studies were identified. The full text of the studies was retrieved and this resulted in 16 articles included in the literature review below. The references of these articles was also searched for relevant studies and resulted in an additional 15 studies." We also got addinitional 5 articles from mendley notification. We also used WHO, AAP, APA guidelines for depression in adolescents.

Prevalence of depression in children with chronic diseases:

According to the WHO, adolescence is defined as age between 10 to 19 years. The prevalence of depression in adolescents is high, as they are a vulnerable category of the population both socially, emotionally, and biologically (5,13–15). The rate is even higher when adolescents presents with chronic diseases such as asthma, diabetes, cancers and HIV (3–5,16–18). Depression is the 9th leading cause of illness and disability in all

adolescents (13), but is also found in all ages, including early childhood The prevalence of depression has been reported to range from 1 to 51% in all children and 15 to 20% in adolescents (13,15).

In India, according to a 2017 report by the central statistics office, the combined prevalence of depression and anxiety among school-going adolescents was reported at 57.65% (15) Extremely severe depression was reported in 3% of all participants. Females were found to be more affected, with a lifetime prevalence of 14.1% versus 8.6% for males (15). A different study was done in India to evaluate the prevalence in school-going adolescents girls revealed the prevalence of depression in 39.3% of this population (15). The WHO reported approximately 53000 adolescents' deaths globally in 2016 due to suicide, which makes it the third leading cause of death in all adolescents in general and the second cause of deaths in female adolescents (13,14).

There is a significant prevalence of depression as a comorbidity of chronic diseases in LMIC (3,5). A cross-sectional study done in Malawi to evaluate the prevalence of depression in adolescents living with HIV using the Children Depression Inventory (CDI) and the Beck Depression Inventory (BDI II) found that the prevalence of depression was at 18.9%, with suicide ideation in 7.1% of these adolescents (5). In Rwanda, a validation study was done in 2016 to evaluate the CDI as a screening tool for depression in children 7-14 years living with HIV found a high prevalence of depression at 25% (3). In 2014 a case-control study done to evaluate children and mental health in Kayonza district in Rwanda, revealed that mental health problems including depression were more prevalent in HIV positive and HIV affected children (who live with an HIV positive relative) than children who were unaffected by HIV (6). A case control study done to evaluate risk and protective factors for suicide ideation and behavior in Rwandan children between 11 and 17 years, living with HIV, affected with HIV (HIV Negative but have an HIV positive Caretaker) and HIV unaffected (HIV Negative and no Known relative with HIV), from Kayonza and Kirehe district. Suicide ideation and behavior were assesses using items from the youth self-report internalizing subscale, whereas behavior were assessed using youth conduct problem scale Rwanda. Findings revealed that 25.7% of all participants scored above depression diagnostic threshold, whereas 20.64 % reported suicide ideation

and 18.30% had attempted to suicide within 6 months before the interview. Rates of depression among three groups of HIV positive, HIV affected and HIV unaffected group were 21.1%, 21.49% and 12.66% respectively (7).

Risk factors for depression

Age: According to Gary R, et al, reported that the onset of depression in less than 12 years is less common, and numbers increase during adolescence (19). Similar findings were also reported by Prager et al, who reported that age as one of the contributing factors for depression (20). Thapar et al, reported lower rate of depression in early childhood compared to in adolescence and adulthood (14). In Uganda, Elizabeth K et al. studied depression and associated factors among adolescents with HIV. They reported more rates in elder adolescents versus younger ones (21).

Gender: Researchers reported some gender differences where female to male ratio were around 2:1 in adolescence (14,15,19). Examples, Thapar et al, reported that though significant difference of depression in adolescence among gender were not evident, there was however high tendency of female adolescents to have more depression than male (14). Gary R et al reported that lifetime depression rate are 8 vs 18%, male to female (19). Alize J. et al. studied the burden of depression by country, age, sex and years, findings from the global burden of diseases, reported more depression in female to male (5.5 vs 3.2%) (22).

Family history of depression: Depression tends to have some genetic component. Researchers reported that children of parents who have depression present three to four times more depression rate compared with the offspring of healthy parents (14,19). The same findings were observed in several twins studies, where they present depression symptoms to a similar extent (14).

Psychosocial risk factors: Several researchers evaluated the possibility of an association between depression and environmental factors (6,14,15,19). Environmental stressors are classified either as acute stressful events (i.e. personal injury, bereavement) or as chronic adversity (i.e. child abuse, family conflicts, bullying by peers, poverty, and physical illness) (14,19,23,24). In most circumstances, they reported that there is an increased risk

of developing depression when the exposure to environmental stressors is added to the genetic susceptibility (14,15,19).

In India, in 2019 the study that evaluated risk factors associated with depression in school going adolescent girls, revealed more depression among girls from the general population. Having educated parents was associated with more depression compared to ones with illiterate parents. Adolescents from privates schools (very competitive schools) were more likely to get depressed (15). In the study done in HIV positive children from 7-14 years old in Rwanda, findings revealed an association of high depression prevalence and people living in the rural area (Western province versus Kigali), however, there was no identified association with other factors such as the orphan status or level of student's education (3). In Uganda, Elizabeth K et al. studied depressive symptoms and associations in adolescents with HIV, they reported more depression in adolescents with poor socio-economic status (i.e. who had to take long journey to the health facility for follow up) with odds ratio of 1.7 (21).

Screening questionnaires for depression: PHQ-9: Patient health questionnaire-9 items

Given the high prevalence of depression in adolescents, few tools were developed for screening for depression in adolescents. PHQ-9 is 9 items self-report questionnaire, designed to assess depression symptoms and severity, where the items are based on the DSM-IV criteria (25,26). It is a multiple-choice self-report, initially developed in 1990 by Pfizer Inc. to be used as a screening and diagnostic tool for a variety of mental health disorders (i.e. depression, anxiety, alcohol, eating, and somatoform disorders) (26). The initial version was known as the Primary Care Evaluation of Mental Disorders (PRIME-MD). This initial version had limited feasibility because it was too long. A shorter version was developed and validated, which is the current PHQ-9 (26,27).

Because PHQ-9 is a quick method to screen and diagnose depression in patients, it is widely used in primary care settings (25,26,28). The questionnaire was initially designed to be auto-administered, but it can also be administered by a trained Health care provider (26). A validation study was done in Indianapolis (US) on 6000 adults followed in 8

primary care and 7 obstetrics and gynecology clinic to validate the use of the PHQ in an adult population revealed both sensitivity and specificity of 88% for a cut-off value of 10, when comparing to the standard mental health interview. The tool has initially been used in adults, however, multiple studies have subsequently been conducted to evaluate its use in adolescents (25,28,29). in different countries and demonstrated a high sensitivity and specificity (25,28–30). A study done in New York, for example, undertaken to screen and diagnose depression in adolescents in a large Health Maintenance Organization (HMO incorporated characteristics of depression in adolescents by including irritability weight loss. When using a cut off of score of 11 (instead of 10 in adults), this study found a sensitivity of 89.5% and specificity of 77.5% (29) The same results were found in two additional studies done in Washington (US) and China to examine the performance characteristics and validity of the PHQ-9 as a screening tool for depression among adolescent (25,28).

The PHQ-9 is translated in more than 20 languages, it is available on the PHQ website in different variants, free of charge, and no permission required for using and copying the measures (26).

In Rwanda, we have a PHQ-9 Kinyarwanda version. The translation was done in 2011 following the coordinated integration of HIV care into mental health, by a group of medical doctors and psychologists. The International Center for HIV/AIDS program (ICAP) of the University of Columbia (US), the mental health division of Rwanda Biomedical Center coordinated this initiative. The forward and back translation approach was used and a discussion group was held for consensus on the cultural equivalence of the translated PHQ-9 (31). Since then, it has been widely used in different hospital settings in Rwanda (Neuropsychiatric hospital and district hospitals) by mental health technicians as a screening and diagnostic tool for depression. The PHQ-9 translated in Kinyarwanda was also validated for use as a screening tool for depression among patients living with Epilepsy in Rwanda and showed that The kinyarwanda translated PHQ-9 had a good reliability with a high degree of internal consistency and temporal stability (31).

Few differences in the PHQ-9 and PHQ-9 modified for adolescents are on items to screen for depressed mood, wherein adolescents also ask about irritability on top of feeling depressed, hopeless and for the item to screen poor appetite or overeating, they add weight loos for adolescents (32). From our Kinyarwanda adult version, we added the 2 items for adolescents' modification. For the irritability, we referred to previous translations done in Kinyarwanda as "Umushiha", and weight loss as "gutakaza ibiro"(24). From there, we obtained a PHQ-9 modified for adolescents in Kinyarwanda that we used in our study.

Sensitivity, specificity and the Cut off scores for the PHQ-9 modified for adolescents

Several validation studies have been carried out to evaluate the sensitivity, specificity, and the cut-off scores of the PHQ-9 use in the screening and diagnosis of depression in adolescents from different countries (25,26,28,30). The cutoff for the diagnosis of depression is between 8 and 11 (30). From the cutoff score of 8 to 11 the sensitivity does not change. It remains 88.9%, but the specificity increases from 63.8% for the cut off score of 8 to 77.5% for 11. (25,30). The recommended cut off score for adolescents screening and diagnosis by the AAP and used in most of the studies on adolescents is 11 (25,28,33). According to the American Psychiatric Association, the PHQ-9 helps to classify depression by severity from mild, moderate, moderately severe to severe depression for scores 5-9, 10-14, 15-19, and above 20 respectively (34).

Other depression screening tools

Different tools such the CDI, BDI, PHQ-9, the John Hopkins depression scale were developed and validated for use in screening and diagnosing depression in children and adolescents, with the last one validated for use in children and early adolescents. (3,5,26). The validation of the BDI and the CDI use has been done in LIMCs, they present with good specificity but the sensitivity was low especially for the CDI (44-76%) in the context of Rwanda, thus requiring an additional clinical assessment to minimize the false negatives (3,5).

Problem statement

Chronic diseases are the leading cause of mortality and morbidity worldwide (1). The Pediatric population is experiencing a significant increase in chronic diseases, especially in low and middle-income countries where these diseases also cause high mortality (10–12). We know that during adolescence, the rates of depression increase significantly as this age group is vulnerable to different environmental stressors, with neuro-biological changes during this period (5,13–15). Rates are even higher in patients with chronic diseases (3,5). Untreated depression worsens the outcomes of chronic disease by accelerating disease progression (i.e. leads to poor medication adherence, poor quality of life) and is associated with suicide attempts. (3,14,19,35). In Rwanda and LMICs in general, we know that depression is a problem in children living with HIV (3,5–7).

There is an increase in the number of children and adolescents with chronic illnesses followed at the Centre d'Excellence Mpore (Pediatric outpatient clinic) at CHUK as there has been an increase in the number of subspecialist pediatricians in the last 5 years. To provide comprehensive care for these children, it is important that co-morbidities are detected in a timely fashion. There is currently no systematic screening in these adolescents who are at high risk of depression. In Rwanda, we need to have a systematic, feasible way to screen our adolescents with chronic diseases so that we can provide the best holistic care. A tool such as the PHQ-9 can be useful to help to identify adolescents with depression.

Research aims and objectives

Research aims

This research aims to improve the outcome of adolescents followed for chronic diseases by providing comprehensive care, including early detection of depression

Research objectives:

1. To determine the prevalence of depression and its severity among adolescents with chronic diseases followed at Centre d' Excellence Mpore (Pediatric outpatient clinic) at CHUK using a patient health questionnaire-9 (PHQ-9) modified for adolescents.

2. To describe the socio-demographic factors associated with depression among adolescents with chronic diseases.

Materials and Methods

Study design

This was a cross-sectional study

Study site

It was done at Centre d'Excellence Mpore (Pediatric outpatient clinic) of CHUK, a tertiary level public hospital, located in the Kigali City; the Capital of Rwanda. Most patients are transferred from more than 14 district hospitals in its catchment area and most of them present to the outpatient center for specialized consultations by pediatric subspecialists or in specialized clinics.

Study population

All adolescents from 12 to 18 years of age, followed for chronic diseases in outpatient clinic of the pediatric department were enrolled.

Study period

The study period started from January 3rd to March 31st 2020

Inclusion criteria

We included all adolescents from 12 to 18 years with chronic diseases followed in the outpatient clinic of the pediatric department of CHUK during the study period, who gave assent and whose parents consented to participate in the study. Despite adolescence being

defined as the ages between 10 and 19 by WHO, we chose to use a cutoff of 12 because the Modified PHQ-9 has not been validated in adolescents younger than 12. We also chose 18 as a cutoff because at CHUK, adolescents with chronic diseases are followed up to the age of 18 years before transitioning to adult care.

Exclusion criteria

We excluded all adolescents needing to be admitted to the hospital as their answers on the PHQ-9 scores could be influenced by different stressors in the hospital (actual illness, being anxious while needing to be hospitalized. We also excluded adolescents with cognitive dysfunctions (i.e. adolescents with cerebral palsy with cognitive dysfunction, adolescents with Down syndrome...) as they might be unable to provide accurate information during data collection.

Sampling methodology and Sample size calculation

We performed a consecutive sampling from January 3rd 2020 until the calculated sample size of 142 participants was reached in March 31st 2020.

We calculated our sample size based on the local prevalence of depression of 25.7% from a study done in Rwanda to evaluate depression in children (11-17 years) living with HIV; and from our database (CHUK), pediatric outpatients, that has a total number of adolescents followed for chronic diseases of 270. The sample size required to estimate a proportion, with a specified level of confidence and precision in a finite population, gave us a sample size of 142 participants. We used the formula mentioned below

$$\frac{\frac{Z^2 \cdot p(1-p)}{e^2}}{1 + \left(\frac{Z^2 \cdot p(1-p)}{e^2 N}\right)}$$

Z: value from standard normal distribution corresponding to the desired confidence level (Z=1.96 for 95% CI)

P: the expected true proportion

E: the desired precision (half-desired CI width)

N: population size

Study procedures

Study instruments

The Modified PHQ-9 for adolescents screening tool was used to screen for depression in adolescents with chronic diseases. It includes nine questions about how the adolescent is feeling over the past 2 weeks' periods. Each question is answered, either by "not at all" (resulting in a score of 0), "several days" (resulting in a score of 1), "more than half the days" (score of 2) or "nearly every day" (score of 3). In the end, the sum of the scores of each question provides the total score, with a positive screening score defined as a score of 11 and above. Besides the PHQ-9 Modified for adolescents, the data collection form had also general demographic information such as adolescent age, sex, ubudehe category, occupation, residency, health insurance, parenting, and medical and family history backgrounds to be completed along with The PHQ-9.

Procedures at enrolment

A trained outpatient nurse screened all adolescents who presented to the pediatric outpatient unit, after they underwent triage. Those found to have a chronic disease, were approached by either the principal investigator or the clinical psychologist and explained the study objectives and details. For those who accepted to participate in the study, written consent was obtained from the caretaker and assent from the adolescents. For adolescents who came without a caretaker, the parent/guardian was called via phone and verbal consent obtained and witnessed by two data collectors. After obtaining consent, adolescents were administered a data collection form that contained the first demographic information. Other medical information needed was obtained from the patient's file and hospital electronic medical records. The second part, which contain the translated PHQ-9 modified for adolescents, was then, completed independently by the adolescents in a quiet, private area of the clinic. The questionnaire were then scored immediately in the office and if they were found to have depression, (i.e. the score of 11 and above); they were first sent to the clinical psychologist for further evaluation and management plan, as this is what is usually done with patients who presents with features of depression at CHUK.

Data Management and analysis

The information obtained during data collection was entered into the statistical package for social sciences (SPSS 25.0) which we also used for data processing and analysis.

We used descriptive statistics to describe categorical variables to obtain frequencies and percentages. We used Chi-Square tests to evaluate the association of factors (demographic and clinical) and having a positive depression screening (PHQ-9 of 11 and above). Results were considered statistically significant for P-Value, which is less than 0.05. We used Fischer's exact test for variables with cell counts less than 5. We used Mendeley software for references management and Vancouver referencing style.

Ethical considerations

The research proposal was reviewed and approved by both the University of Rwanda, College of Medicine and Health Sciences institutional review board, Approval Notice: No 539/CMHS IRB/2019 (appendix 3) and CHUK research and ethics committee (appendix 4).

Informed consent

The purpose of this study was explained to both adolescents and parents/guardians and assents/consents were obtained prior to the beginning of data collection from both adolescents and guardian. For guardians who were not available at the time of participants' recruitment, the consent was obtained via phone call and witnessed by two data collectors (nurse, psychologist).

Confidentiality

The information collected was protected with a password and the names were not on the questionnaire. A unique patient identifier was used to protect the data and identifiers were kept in a separate password protected spreadsheet. While explaining the purpose of the study to the adolescents and the filling of the questionnaire, adolescents were taken into a separate room (psychologist office) to ensure their privacy.

Risks to the participants

There was no physical, social, legal and financial risk identified during enrolment and data collection.

The emotion risk to adolescents and/or guardian who might feel uncomfortable when the adolescent is identified as having depression was mitigated while obtaining the informed consent, by clearly explaining the role of early detection of depression in case it present and all the next steps to be taken in order to help the adolescents who screened positive.

Results

Study participant enrolment

During the study period from January 3rd till March, 31st 694 children consulted the Centre d'Excellence Mpore (CEM), the ediatric outpatient clinic of the University Teaching Hospital of Kigali). Among them, 257 were adolescents aged 10 to 18, and 186 were followed for chronic diseases and came for their regular appointment. 142 met the inclusion criteria and were approached and after they have consented to participate in the study, they were administered a PH-9 Questionnaire modified for adolescents along with the data collection form.

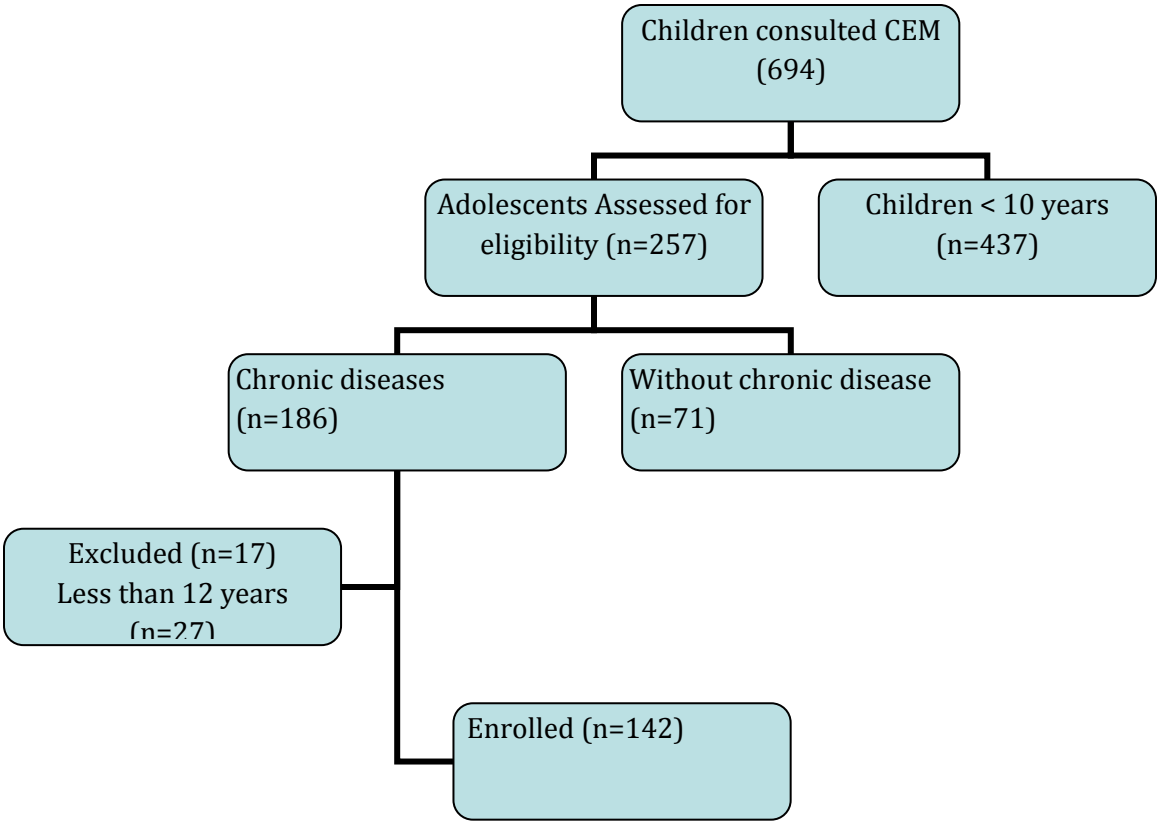

Figure 1. Patient recruitment in the study

Among 17 adolescents excluded, 10 refused to participate, 3 had cognitive dysfunction (unable to respond to questions), 4 were too ill to be interviewed.

Table 1: Participants' socio-demographic characteristics

Characteristics	Number /frequency (n=142)	Percentage
Adolescent age group		
• Early adolescence (12-14 years)	61	43.0 %
• Late adolescence (15- 18 years)	81	57.0 %
Sex		
• Male	64	45.1 %
• Female	78	54.9 %
Province of residence		
• Kigali city	100	70.4 %
• Southern province	19	13.4 %
• Northern province	10	7.0 %
• Eastern province	8	5.6 %
• Western province	5	3.5 %
Ududehe category		
• Category I	15	10.6 %
• Category II	45	31.7 %
• Category III	82	57.7 %
Health insurance scheme		
• CBHI	123	86.6%
• RSSB	14	9.9 %
• Private/institution-based	5	3.5 %
Adolescent Level of education		
• Primary	73	51.4 %
• Secondary	68	47.9 %
• University	1	0.7 %
Home living situation		
• Lives with both parents	66	46.5 %
• Only live with mother	48	33.8 %
• Only live with father	6	4.2 %
• Lives with a guardian/relative	20	14.1 %
• Lives with a non-relative guardian	2	1.4 %
School description		
• Public	97	68.3 %
• Private	45	31.7 %
type of school		
• Boarding	23	16.2 %
• Non-boarding	119	83.8 %

A total number of 142 adolescents were included. The male to female ratio was 1: 1.2. The median age was 15, the lowest quarter comprise adolescents in 12 and 13 years, and the highest quarter comprise 16 to 18 years. 43.0% were in early adolescence and 57%

were in late adolescence. Even though more than half were "older adolescents", half were still in primary school, reflecting an educational delay as older adolescents should be in high school.

Adolescents came from all over the country though Kigali was more represented with 70.4% of adolescents.

Adolescents live in families with different socio-economic backgrounds. However more than half of our population (57.7%) were In Ududehe category 3. All participants had health insurance; however, 86.6% of adolescents use the community-based health insurance, and followed by 9.9% with RSSB medical health scheme.

46.5% of adolescents live with both parents, 38.0 % live with one parent, whereas 15.5% live with guardians

Table 2: Clinical characteristics and Modified PHQ-9 screening result

Characteristics	**Numbers/frequency (n= 142)**	**Percentage**
Chronic disease type		
• Cardiac	24	16.9 %
• Respiratory	9	6.3 %
• Hematological	11	7.7 %
• HIV	82	57.7 %
• Diabetes Mellitus	3	2.1 %
• Kidney diseases	10	7.0 %
• Others	3	2.1 %
Overall PHQ-9 Score		
• 0 to 4	50	35.2 %
• 5 to 10	59	41.5 %
• 11 to 14	22	15.5 %
• 15 to 19	9	6.3 %
• 20 to 27	2	1.4 %
Total screened positive for depression		
Depression severity		
• Moderate depression (score 11 to 14)	22	15.5 %
• Moderately severe (score 15 to 19)	9	6.3 %
• Severe depression (score 20 to 27)	2	1.4 %
Total screened positive depression	33	23.2 %

Table 2 indicates results of depression screening, using a PHQ-9 modified for adolescents. The maximum possible final score obtained is 27. The final score classifies the adolescents as having moderate, moderately severe, and severe depression based on

scores of 11 to 14, 15 to 19 and 20 to 27 respectively. Among 142 adolescents, 33 adolescents representing 23.2% were screened positive for depression (i.e. scores equal and above to 11). Among them, 15.5% had moderate depression, 6.3% had moderately severe depression and two adolescents resenting 1.4% had severe depression. Though HIV was the most represented as a chronic disease in 57.7%, we also had adolescents with cardiac, respiratory, hematological, kidney, respiratory diseases and diabetes as mentioned in table 2. All adolescents had no previous history of mental illnesses. Six adolescents representing 4.2% of adolescents have a closer relative (direct sibling or parent) with a positive history of mental illnesses (have consulted mental health department), with 4 of these relatives having schizophrenia (diagnosed at the neuropsychiatric hospital), and 2 having other unspecified mental illness.

Table 3: Association of depression to socio-demographic factors

Characteristics	Positive screen for depression	Negative screen for depression	Chi-square value	P-value
Adolescence age category				
• Early adolescence	13 (21.3%)	48 (78.7%)	0.223	0.637
• Late adolescence	20 (24.7%)	61 (75.3%)		
Sex				
• Male	17 (26.6%)	47 (73.4%)	0.721	0.396
• Female	16 (20.5%)	62 (79.5%)		
Province of residence				
• Kigali city	20 (20.0%)	80 (80.0%)		
• Southern province	9 (47.4%)	10 (52.6%)	7.815	0.09
• Northern province	1 (10.0 %)	9 (90.0 %)		
• Eastern province	2 (25.0 %)	6 (75.0 %)		
• Western province	1 (20.0 %)	4 (80.0 %)		
Ududehe category				
• I	3 (20.0 %)	12 (80.0 %)		
• II	7 (15.6 %)	38 (84.4 %)	2.641	0.267
• III	23 (28.0 %)	59 (72.0 %)		
Parenting				
• Live with both parents	20 (30.3%)	46 (69.7 %)		
• Only live with the mother	8 (16.7%)	40 (83.3 %)		
• Only live with the father	0 (0.0 %)	6 (100.0 %)	5.465	0.243
• Live with a guardian	5 (25.0 %)	17 (75.0 %)		
Adolescent level of education				
• Primary	15 (20.5 %)	58 (79.5%)		
• Secondary	18 (26.5 %)	50 (73.5 %)	0.997	0.607
• University	0 (0.0 %)	1 (100.0 %)		
Current adolescent school				
• Private	10 (22.2 %)	35 (77.8 %)	0.038	0.845
• Public	23 (23.7 %)	74 (76.3%)		
• Boarding	1 (4.3 %)	22 (95.7 %)	5.491	0.019
• Non boarding	32(26.9%)	87 (73.1 %)		
Type of chronic diseases				
• Cardiac	8 (33.3 %)	16 (66.7 %)		
• Respiratory	1 (11.1 %)	8 (88.9 %)		
• Hematological	4 (36.4 %)	7 (63.6 %)		
• HIV	17 (20.7 %)	65 (79.3 %)	4.789	0.571
• Diabetes	1 (33.3 %)	2 (66.7 %)		
• Kidney diseases	1 (10.0 %)	9 (90.0 %)		
• Others	1 (33.3 %)	2 (66.7 %)		
A close relative with mental illness				
• Known mental illness	2 (33.3.0 %)	4 (66.7.0 %)	0.825	0.662
• No mental illness	31 (22.8 %)	105 (77.2 %)		

We assessed the association between screening positive for depression and factors suchas sex, age group, province of residence, socioeconomic status, parenting, level of education, current school, type of chronic diseases, and having a positive family history of mental illness.

We found evidence of an statistically significant association between having screened positive for depression in adolescents currently studying in non-boarding schools compared to adolescent in boarding schools (26.9 vs 4.3%, p-value: 0.019). Fischer exact test was also performed and revealed the same significance (p value: 0.016).

There was a slight higher prevalence of depression in males adolescents compared to females (26.6 vs 20.5 %) , in older adolescents compared to younger adolescents (24 vs 20%), in adolescents from Ududehe category 3 to the remaing categories (28.0 vs 15.6 - 20%), in adolescent living with both parents to both single or double orphans (30 vs 0 to 16.7%) and adolescents in secondary schools to primary and university (26.5% vs 0 to 20.5%) but differences were not statistically significant (Table 3). There was also a higher prevalence in depression among adolescents from the southern province (47.4% vs 10-25% for the other provinces). Although this was not under our threshold for significance, this trended toward significance with a p-value of 0.09. We found some differences where adolescents with non-HIV chronic diseases have a bit higher rate for depression at 26.7% versus 20.7% in those with HIV. However there is no statistical significance as the p-value for both chi-square was not significant (P value: 0.408).

Discussion

Prevalence of depression

Depression in adolescence is a global public health challenge, with prevalence of depression being high in adolescents with chronic diseases. This is due to the chronic need for seeking regular consultation, social isolation, and stigma and also being concerned about their future (3,5,15). In this study, a modified PHQ-9 screening questionnaire was given to 12-18-year-old adolescents with chronic diseases attending the pediatric outpatient center of CHUK during a period of 3 months. Among the 142 adolescents included, there is a high prevalence of depression, with 23 % of adolescents having depression and 1.4% having severe depression.

This high prevalence rate is very close to the prevalence found in studies done in different settings in children and adolescents living with HIV. For example, a study done in Rwanda by Binagwaho et al., on validating the children's depression inventory in the context of Rwanda, in children (7-14 years) living with HIV, revealed a prevalence of depression at 25% using a clinical interview (3). A match case control study done in youth (11-17 years) living and affected by HIV in Kayonza district by Lauren C et al, that looked at risk and protective factors for suicidal ideation and behavior in Rwandan children, found slightly higher prevalence of depression at 25.7% (7). Another study done in Rwanda to look at depressive symptoms in youth heads of households by Neil. W et al. revealed a prevalence of depression in 24.4% of youths, using the center for epidemiological studies depression scale (36). Our findings are slightly higher than in Malawi, where the Beck depression inventory was validated among adolescents with HIV and where the prevalence of depression was 18.9%. (5). Around 1/4 of our adolescents in our study, met criteria for depression. A third of them had moderately severe to severe depression, which is very important to consider as we know that depression negatively impacts the quality of life, by accelerating chronic diseases progression (3,17,21,37–39). Other studies in Rwanda demonstrated similar rates of moderate and severe depression; however, in our clinic, we have no systematic way to screen for depression among these adolescents. A modified PHQ 9 for adolescents is a simplified tool than can be used, even

in a primary care setting (29,40), it has a good reliability and accuracy as demonstrated in different validations done before (28–30), and provided results that are closer to the ones obtained in previous studies in Rwanda , where other tools were used. PHQ-9 can be used in a systematic way to help in early identification of those adolescent who may have depression as comorbid to chronic diseases. A further study should evaluate the rate of depression in adolescents without chronic diseases, adolescents in schools and in the general population and should be validated by systematically following up on adolescents who are at high rates of depression.

Socio-demographic factors

Results from our study mentioned that overall, sociodemographic factors (i.e. adolescents' age group, sex, province of residence, socioeconomic status, parenting, and adolescents' level of education), adolescents' medical and family backgrounds were not associated with having a positive depression screening result. However, although it was not statistically significant, there was a trend toward significance when comparing adolescents from the southern province, in whom the prevalence of depression was more than twice as high as the rate of depression of adolescents from other provinces. The difference in depression prevalence has also been noted by Binagwaho et al found who more depression in children from western province compared to children in Kigali (3). The other differences in the rates of depression that were noted, such as males having a higher prevalence than females are not statistically significant. This could have been due to the limited sample size as in our study as our sample size was calculated with a formula to estimate proportion in a population and not based on a measure of association. Other studies have found that some of the socio-demographic factors such as higher socio-economic or residence (cities vs countryside), parenting and parental education are associated with having a positive depression (3,7,15,36), so it is possible that these are not statistically significant in our study because it was not powered to detect this association. One example of a study done in Rwanda to look at depressive symptoms in youth heads of households by Neil. W et al. revealed than among the 24.4% of youth screened positive for depression using the center for epidemiological studies depression scale, had some poor socioeconomic status (36). On the other side, in a study from India,

adolescents from families with higher socio economic status, highly educated parents had more depression compared to families in low socioeconomic status, and illiterate parents (15). Adolescents in non-boarding schools were more likely to screen positive for depression compared to adolescents in boarding schools, and this is the only socio-demographic factor which was statistically significant (P-Value: 0.019). This study was not designed to determine the reasons children not in boarding school have higher rates of depression. However, based on our clinical practice in Rwanda, one could hypothesize that this is maybe due to the facts that those in non-boarding schools have more stressors in their environment, such as less structure, being pushed by their parents/guardian to work harder or being more exposed to family conflicts and adverse experiences,..), compared to the ones in boarding schools who receive continuous support from peers, who have time for regular activities such as physical exercises, social and fun clubs. There are no other studies that specifically looked that the differences in rates of depression between children in boarding vs non-boarding. Slightly higher percentage of depression in adolescents with chronic diseases other than HIV versus adolescents with HIV was found in our study. Though our sample size was not powered to detect this difference, one could hypothesize that adolescent with HIV have a well-structured way of follow up, they have support groups where they exchange ideas, compared to adolescent followed for non-HIV chronic diseases who only attend clinic once every 3 months. Studies done previously were looking at the depression in adolescents with each chronic disease but did not compare its rate among different types of chronic diseases (4,6,17,18,41).

Limitations

There were some limitations to our study. The first one was a small sample size, where it was difficult to conclude on whether the lack of association between studied factors and a positive depression was due to a lack of statistical significance or if it was just due to the fact that our sample size was not powered to detect the association between factors and having positive depression. Besides that, the distribution of participants was challenging as most of them were from Kigali city and the majority of them had HIV as a chronic disease. Hence it hard to conclude on the null hypothesis found on the association

between these factors (province of residency and types of chronic diseases) and having positive depression screening. Even though our participants were followed regularly at the pediatric center of excellence, where most of them receive regular psychosocial support, they still have high rate of depression. This means that we probably have even more depression rate than that in our adolescents, especially for those who have poor follow up. Hence, it is difficult to generalize the findings, as they may not reflect the true proportion of depression in the entire population of adolescents with chronic diseases in Rwanda.

Recommendations

Depression among adolescents with chronic diseases is a big challenge given the high prevalence in our population (23.0 %). However, due to the above-mentioned limitation, a multicenter study is required to provide more information on the prevalence of depression and its associated socio-demographic factors among adolescents with chronic diseases.

In our settings, we have no systematic way to screen for depression among these adolescents. A modified PHQ-9 for adolescents is a simplified tool than can be used, even in primary care settings to early identify those adolescents in need and help them used. It would also be interesting to know what is the rate of depression in adolescents without chronic diseases, adolescents in schools and in the general population using a modified PHQ9 for adolescents.

Conclusion

Our study demonstrated that depression is prevalent among adolescent with chronic diseases, hence the need for integration of mental health into the management of chronic diseases to identify theses adolescent and help them timely to improve their outcomes. A tool like PHQ-9 modified for adolescents can be helpful to screen them, and it is paramount to identify other associated socio-demographic factors and get them addressed.

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Appendices

Appendix 1: Literature search string

(Depression) AND ((Chronic disease) OR (HIV)) AND (Adolescent) AND (Screening) NOT ((Adult) OR (Prenat*))

Appendix 2: Data collection form

Section 1: Completed by a data collector (A trained nurse or psychologist)

M: Male, F: Female, DNA: Does not apply (or/and unknown), MUSA: Community Health Insurance (Mutuelle de Santé)

RSSB: Rwanda Social Security Board, MMI: Military Medical Insurance

Study ID Number	
Demographics	
Patient date of birth	
Date of admission	
Sex	☐ F ☐ M
Residence (District)	
Parent/guardians Ududehe Category	☐ 1 ☐ 2 ☐ 3 ☐ 4
Health insurance	☐ MUSA ☐ MMI ☐RSSB ☐ Private insurance ☐ None
Orphan status	☐ Live with both parents ☐ Only live with the mother ☐ Only live with the father ☐ doesn't like with father or mother but lives with another family member ☐doesn't live with any family member
Adolescent level of education (year of study)	

Current school	☐ Private ☐ Public ☐ Boarding ☐Non-boarding
Maternal Education (highest level completed)	☐ None ☐ Primary ☐ Secondary ☐ Post-secondary ☐ DNA
Paternal Education(highest level completed)	☐ None ☐ Primary ☐ Secondary ☐ Post-secondary ☐ DNA
The number of people living at home (including the patient).	
Present and past medical history	
Type of chronic diseases (current diagnosis)	☐ Cardiac diseases ☐ Respiratory diseases (asthma, TB,…) ☐ Hematologic diseases (Hemophilia, SCD, ITP, …) ☐ Cancers (Leukemia, Lymphoma, Nephroblastoma…) ☐ HIV ☐ Diabetes Mellitus ☐ Renal diseases (Nephrotic SD, CKD…) ☐ others :_____
Any other known diagnosed psychiatric illness	☐ Yes ☐ NO
If any (psychiatric illness) which one	
Any close relative(direct siblings and parents) with depression or psychiatric illness. (”Are there any close relative, direct siblings or parents who have been diagnosed or are being treated for depression or any other psychiatric illness”?)	☐ Yes ☐ NO
If any (psychiatric illness) which one	

Section 2: PHQ-9 To be completed by either an adolescent or a data collector (Trained nurse or a psychologist).

PHQ-9 Modified for Teens (English version)

Instructions: How often have you been bothered by each of the following symptoms during the **past two weeks**? For each symptom put an "X" in the box beneath the answer that best describes how you have been feeling.

For each symptom put an "X" in the box beneath the answer that best describes how you have been feeling.

I.

	(0) Not At All	(1) Several Days	(2) More Than Half the Days	(3) Nearly Every Day
1. Feeling down, depressed, irritable, or hopeless?				
2. Little interest or pleasure in doing things?				
3. Trouble falling asleep, staying asleep, or sleeping too much?				
4. Poor appetite, weight loss, or overeating?				
5. Feeling tired, or having little energy?				
6. Feeling bad about yourself — or feeling that you are a failure, or that you have let yourself or your family down?				
7. Trouble concentrating on things like school, work, reading, or watching TV?				
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you were moving around a lot more than usual?				
9. Thoughts that you would be better off dead, or of hurting yourself in some way?				
	Total Score			

PHQ-9 Modified for Teens (Kinyarwanda version)

Mu byumweru bibiri bishize, ni kangahe waba waribonyeho ibimenyetso bikurikira: (*shyira akamenyetso kugisubizo kiboneye)*

	(0) Nta na rimwe	(1) Rimwe na rimwe	(2) Birenze iminsi 7	(3) Hafi ya buri munsi mu gihe cy'ibyumweru 2
1. Kumva ubabaye, ufite ishavu, wihebye , cyangwa ufite umushiha.				
2. Kudashishikarira ibyo ukora cyangwa ntushimishwe nabyo				
3. Kubura ibitotsi, kubicikiriza hagati mu ijoro bikakugora kongera gusinzira cyangwa gusinzira bikabije				
4. Kugira umunaniro udashira cyangwa ukumva ufite imbaraga nkeya cyane				
5. Kumva udashaka kurya, kurya cyane bidasanzwe cyangwa gutakaza ibiro?.				
6. Kwitekerezaho cyane kandi nabi, kumva nta kamaro ufite, kumva ntacyo wimariye cyangwa umariye umuryango wawe				
7. Kumva udashishikajwe n'ibintu, cyangwa se imirimo wari usanzwe ukora, nko kwiga, gusoma cg se kureba television, kuganira n'abo mubana, n'ibindi.				
8. Kugenda cyangwa kuvuga buhoro kuburyo budasanzwe bikagaragarira abandi, cyangwa kugendagenda, ntugume hamwe nk'ibisanzwe				
9. Gutekereza ko gupfa byakurutira byose cyangwa ukumva wakwigirira nabi.				
	Igiteranyo			

Appendix 3: CMHS- IRB

UNIVERSITY of RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES

DIRECTORATE OF RESEARCH & INNOVATION

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 5th /December/2019

Dr NIYIGABA Jean Pierre
School of Medicine and Pharmacy, CMHS, UR

Approval Notice: No 539/CMHS IRB/2019

Your Project Title ***"The Screening of Depression among Adolescents with Chronic Diseases in a Tertiary Level Hospital in Rwanda"*** has been evaluated by CMHS Institutional Review Board.

		Involved in the decision		
			No (Reason)	
Name of Members	**Institute**	Yes	**Absent**	**Withdrawn from the proceeding**
Prof Kato J. Njunwa	UR-CMHS	X		
Prof Jean Bosco Gahutu	UR-CMHS	X		
Dr Brenda Asiimwe-Kateera	UR-CMHS	X		
Prof Ntaganira Joseph	UR-CMHS	X		
Dr Tumusiime K. David	UR-CMHS			X
Dr Kayonga N. Egide	UR-CMHS	X		
Mr Kanyoni Maurice	UR-CMHS		X	
Prof Munyanshongore Cyprien	UR-CMHS	X		
Mrs Ruzindana Landrine	Kicukiro district		X	
Dr Gishoma Darius	UR-CMHS	X		
Dr Donatilla Mukamana	UR-CMHS	X		
Prof Kyamanywa Patrick	UR-CMHS		X	
Prof Condo Umutesi Jeannine	UR-CMHS		X	
Dr Nyirazinyoye Laetitia	UR-CMHS	X		
Dr Nkeramihigo Emmanuel	UR-CMHS		X	
Sr Maliboli Marie Josee	CHUK	X		
Dr Mudenge Charles	Centre Psycho-Social	X		

After reviewing your protocol during the IRB meeting of where quorum was met and revisions made on the advice of the CMHS IRB submitted on 5th December 2019, **Approval has been granted to your study.**
Please note that approval of the protocol and consent form is valid for **12 months**.

Email: researchcenter@ur.ac.rw P.O Box 3286 Kigali, Rwanda www.ur.ac.rw

You are responsible for fulfilling the following requirements:

1. Changes, amendments, and addenda to the protocol or consent form must be submitted to the committee for review and approval, prior to activation of the changes.
2. Only approved consent forms are to be used in the enrolment of participants.
3. All consent forms signed by subjects should be retained on file. The IRB may conduct audits of all study records, and consent documentation may be part of such audits.
4. A continuing review application must be submitted to the IRB in a timely fashion and before expiry of this approval
5. Failure to submit a continuing review application will result in termination of the study
6. Notify the IRB committee once the study is finished

Sincerely,

Date of Approval: The 5th December 2019

Expiration date: The 5th December 2020

Professor GAHUTU Jean Bosco
Chairperson Institutional Review Board
College of Medicine and Health Sciences, UR

Cc:

- Principal College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate Studies, UR

Appendix 4: CHUK Ethics committee review approval notice

CENTRE HOSPITALIER UNIVERSITAIRE
UNIVERSITY TEACHING HOSPITAL

Quality Health Care
Training & Research

Ethics Committee / Comité d'éthique

17,Apr,2020 Ref.:EC/CHUK/021/2020

Review Approval Notice

Dear Jean Pierre Niyigaba,

Your research project: ***"The screening of depression among adolescents with chronic diseases in a tertiary level hospital in Rwanda "***

During the meeting of the Ethics Committee of University Teaching Hospital of Kigali (CHUK) that was held on 17,Apr,2020 to evaluate your request for ethical approval of the above mentioned research project, we are pleased to inform you that the Ethics Committee/CHUK has approved your research project.

You are required to present the results of your study to CHUK Ethics Committee before publication by using this link:www.chuk.rw/research/fullreport/?appid=63&&chuk.

PS: Please note that the present approval is valid for 12 months.

Yours sincerely,

Dr Emmanuel Rusingiza Kamanzi
The Chairperson, Ethics Committee,
University Teaching Hospital of Kigali

ETHICS COMMITTEE
CHUK

Scan code to verify.

" University teaching hospital of Kigali Ethics committee operates according to standard operating procedures (Sops) which are updated on an annual basis and in compliance with GCP and Ethics guidelines and regulations "

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