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Advancing Equitable, Evidence-Informed and People-Centred Healthcare

HIGHLIGHTS

1. Predicting Loss to Follow-Up in HIV Care
2. Second-Dose Measles Vaccine Uptake in Rusizi
3. Early Intervention Services for Developmental Delays
4. Sociocultural Perspectives on Palliative Care in East Africa

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Contacts

Email: rwandapublichealtbulletin@gmail.com
Website: https://www.rbc.gov.rw/publichealthbulletin/

Address

Rwanda Public Health Bulletin Secretariat
KG 203St., City of Kigali, Rwanda

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CONTENT

Dear readers,

It is my pleasure to present Volume 7, Issue 2 of the Rwanda Public Health Bulletin (RPHB), a publication that reflects Rwanda's continued commitment to generating, sharing, and applying high-quality evidence to improve population health and strengthen our health system.

The articles featured in this issue are united by the theme *"Advancing Equitable, Evidence-Informed and People-Centred Healthcare."* Together, they address important public health priorities across the continuum of care, including retention of women in HIV treatment, childhood immunization, early intervention services for children with developmental delays, and the sociocultural dimensions of palliative care. Although these studies address different populations and health challenges, they share a common message: achieving better health outcomes requires health services that are accessible, responsive, equitable, data-driven, and centred on the needs of individuals, families, and communities.

This issue also demonstrates the growing importance of innovation and the effective use of routine health data. The policy brief on predicting loss to follow-up among women receiving HIV care illustrates how machine learning and predictive analytics can support earlier identification of individuals at risk of disengagement and enable more targeted interventions. At the same time, the research on measles vaccination highlights the continuing importance of addressing practical barriers such as distance, transport costs, waiting times, caregiver knowledge, and vaccine availability.
The findings on early intervention services for children with developmental delays remind us that strong health systems depend not only on infrastructure and technology, but also on capable healthcare professionals, effective referral pathways, multidisciplinary collaboration, and meaningful engagement with families. Similarly, the evidence on palliative care reinforces the importance of understanding and responding to the cultural and social contexts that shape healthcare experiences and access to services.

These contributions are particularly relevant as Rwanda continues to advance universal health coverage, strengthen primary healthcare, embrace digital transformation, and promote the use of evidence in policy and practice. Research achieves its greatest value when its findings move beyond publication to inform decisions, improve programmes, guide resource allocation, and ultimately contribute to better health outcomes.

I commend the authors for their valuable contributions and acknowledge the reviewers, editors, and editorial team whose dedication and scientific rigour have made this issue possible. I also extend my appreciation to our national and international partners for their continued collaboration in strengthening Rwanda's public health research and knowledge ecosystem.

I encourage readers to engage critically with the evidence presented in this issue and, most importantly, to consider how these findings can be translated into practical action. By connecting research with policy and implementation, we can continue to build a resilient, innovative, equitable, and people-centred health system that leaves no one behind.

RWANDA BIOMEDICAL CENTER

Prof. Claude Mambo Muvunyi, MD, PhD
Editor-In-Chief -The Rwanda Public Health Bulletin (RPHB)
Director General- The Rwanda Biomedical Centre (RBC)

Predicting and Preventing Loss to Follow-Up Among Women in HIV Care in Rwanda, 2025: A Machine Learning Approach - Policy brief

Christian Ndinda[1,*], Claude Kwizera[1], Fatima[1], Emmanuel Ngwakongnwi[2], Odette Nishimwe[2]

[1]*Rwanda Biomedical Centre (RBC), Kigali, Rwanda*
[2]*University of Global Health Equity (UGHE), Kigali, Rwanda*

***Corresponding author:**
Christian Ndinda

Rwanda Biomedical Centre (RBC), Kigali, Rwanda

Email: christian.ndinda@rbc.gov.rw

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KEY MESSAGES

Rwanda has achieved the global 95–95–95 HIV targets, but sustaining retention in HIV care remains essential for maintaining viral suppression and reducing HIV-related morbidity and mortality.

Women receiving antiretroviral therapy (ART), especially younger women and those experiencing treatment or demographic instability, remain at increased risk of loss to follow-up (LTFU).

Machine learning models using routine national HIV case-based surveillance (CBS) data can accurately identify women at high risk of disengagement before prolonged interruption of care occurs.

Random Forest models demonstrated strong predictive performance for identifying women at risk of LTFU, with recall performance of 73.9% and an AUC of 78%.

Integrating predictive analytics into Rwanda's national HIV program could strengthen differentiated service delivery, improve targeted retention interventions, and reduce avoidable treatment interruption among women living with HIV.

PROBLEM STATEMENT

Rwanda has made substantial progress in HIV prevention, treatment, and care over the past decade. The country has achieved the UNAIDS 95–95–95 targets, with most people living with HIV aware of their status, receiving antiretroviral therapy (ART), and achieving viral suppression [1]. Despite these achievements, maintaining long-term retention in HIV care remains a major public health priority.

Retention in HIV care is essential for sustained viral suppression, prevention of HIV transmission, reduction of opportunistic infections, and improved survival outcomes [2,3]. However, some women receiving ART continue to experience interruptions in care due to social, clinical, behavioral, and structural factors. Pregnancy, postpartum transitions, regimen modifications, delayed ART pickups, and geographic mobility can all disrupt continuity of treatment and increase the risk of disengagement from care.

Loss to follow-up (LTFU) among women living with HIV has serious implications for both individuals and the national HIV program. Women who disengage from care are at increased risk of viral rebound, treatment failure, drug resistance, preventable hospitalizations, and HIV-related mortality [2,3]. At program level, LTFU reduces efficiency, increases the burden on healthcare systems, and threatens national HIV epidemic control goals.

Current retention approaches within routine HIV programs are largely reactive. Women

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are often identified only after repeated missed visits or prolonged absence from care. This limits opportunities for early intervention and increases the likelihood of treatment interruption. Routine monitoring systems frequently fail to identify subtle warning signs of instability before disengagement occurs [2,6].

Rwanda's national HIV case-based surveillance (CBS) platform offers an important opportunity to strengthen retention strategies through predictive analytics. By using routine clinical and programmatic data, machine learning models can identify women at highest risk of LTFU before interruption becomes prolonged. Similar approaches using machine learning in HIV care have demonstrated promising results in improving early identification of patients at risk of disengagement and poor treatment outcomes in other settings [6,7].

EVIDENCE AND FINDINGS

This policy brief is based on analysis of anonymized national CBS data from 33,191 women receiving ART in Rwanda between 2020 and 2025. The study used longitudinal routine program data reflecting real-world HIV service delivery conditions across the country.

Loss to follow-up was defined as absence of clinic or pharmacy contact for 90 days or more after the expected visit date. Multiple demographic, clinical, behavioral, and facility-level variables were extracted and analyzed. Four machine learning algorithms were developed and compared, including Random Forest, XGBoost, LightGBM, and CatBoost. To improve model performance for imbalanced health data, under-sampling and Synthetic Minority Oversampling Technique (SMOTE) approaches were applied.

Overall, 1.4% of women in the analytic sample were classified as LTFU. Among the tested models, Random Forest with under-sampling performed best overall, with an accuracy of 71.8%, recall of 73.9%, and area under the curve of 78%. Model performance comparison is presented in Table 1.

The analysis identified several major predictors associated with increased risk of LTFU among women receiving ART, including frequent art regimen changes, longer intervals since last art pickup, delayed viral load suppression, recent demographic changes or instability, younger age groups, and geographic mobility. On the other hand, protective factors associated with improved retention included clinical stability, older age, completion of tuberculosis preventive therapy (TPT), fewer opportunistic infections, and residence in northern, western, and southern provinces compared with eastern province.

The findings demonstrate that LTFU among women in HIV care is not random. Instead, it clusters around identifiable clinical and programmatic indicators already available within routine national data systems. This suggests that predictive analytics can feasibly be integrated into Rwanda's HIV program to support earlier intervention and strengthen differentiated service delivery.

POLICY OPTIONS

To reduce LTFU among women receiving HIV care in Rwanda, it is essential to strengthen early identification of women at risk of disengagement and improve targeted retention interventions. Current retention systems are effective but remain largely reactive, often identifying women only after prolonged interruption of care has already occurred [1-3]. To address this challenge, two policy options have been proposed and compared with the status quo below.

Policy Option 1: *Status Quo*

What: Continue existing HIV retention strategies based on routine appointment tracking, adherence counseling, community health worker follow-up, differentiated service delivery, and tracing of women after missed visits.

Table 1: *Model performance comparison*

Model	Accuracy	Recall	Area Under the Curve (AUC)
Random Forest	0.718	0.739	0.780
XGBoost	0.585	0.782	0.744
LightGBM	0.692	0.753	0.776
CatBoost	0.723	0.662	0.762

Challenge: Although Rwanda has achieved strong HIV treatment outcomes [2], routine retention systems often identify women only after missed visits or prolonged absence from care. This limits opportunities for early intervention and increases the risk of viral rebound, treatment failure, and permanent disengagement from care. Current approaches also make it difficult to prioritize women at highest risk of LTFU using available routine data.

Policy Option 2: *Integrating Machine Learning Risk Prediction into the National HIV Case-Based Surveillance (CBS) Platform*

What: Integrate machine learning–based predictive analytics into the national HIV CBS platform to identify women at high risk of LTFU before prolonged disengagement occurs.
Why: Analysis of national HIV routine data demonstrated that machine learning models can accurately identify women at increased risk of disengagement from HIV care. The Random Forest model achieved strong predictive performance with a recall score of 73.9% and an AUC of 0.780. Key predictors of LTFU included frequent ART regimen changes, delayed ART pickup, delayed viral load suppression, younger age, and demographic instability.
Using predictive analytics would allow healthcare providers, data managers, and community health workers to intervene earlier among women at highest risk. This would strengthen differentiated service delivery, improve continuity of treatment, and reduce preventable treatment interruption.
How: Risk prediction algorithms would be integrated into the national CBS platform to generate automated risk scores for women receiving ART. Women identified as high risk would receive targeted retention interventions such as enhanced adherence counseling, active tracing, peer support, closer follow-up during pregnancy and postpartum periods, and fast-track refill or multi-month dispensing services.
Implementation should begin through phased pilot testing in high-volume facilities and high-mobility districts before national scale-up. Standard operating procedures should guide ethical use of predictive analytics, data governance, confidentiality, and clinical action thresholds.

Feasibility: *High.* Rwanda already has a strong national HIV case-based surveillance infrastructure and well-established differentiated service delivery models. The predictive model uses routinely collected national HIV data, making implementation operationally feasible within the existing HIV program structure.

Policy Option 3: *Strengthening Targeted Retention Support for High-Risk Women*

What: Strengthen targeted retention interventions for younger women and women identified with clinical or social instability associated with increased risk of LTFU.
Why: Women aged 18–24 years, women with delayed ART pickups, regimen changes, demographic instability, and delayed viral suppression were more likely to disengage from care. Targeted support for these groups can improve adherence, reduce missed visits, and strengthen long-term retention in HIV care.
How: Healthcare providers and community health workers would provide intensified adherence counseling, active follow-up, peer support, appointment reminders, and closer clinical monitoring for women identified as high risk. The national HIV program would also expand multi-month dispensing, community ART delivery, and fast-track refill systems to reduce structural barriers to care.
Feasibility: *High.* Rwanda already implements differentiated HIV service delivery models and community-based follow-up mechanisms. These systems can be adapted to prioritize women identified as high risk for LTFU.

RECOMMENDATIONS AND NEXT STEPS

The Rwanda Biomedical Centre should integrate machine learning–based risk prediction into the national HIV case-based surveillance platform to support earlier identification of women at high risk of loss to follow-up. Implementation should begin through phased pilot testing in high-volume facilities and high-mobility districts before national scale-up.
Younger women, especially those aged 18–24 years, and women experiencing recent regimen changes, delayed ART pickups, or demographic instability should receive intensified retention support. Enhanced adherence counseling, active follow-up, peer support, and closer monitoring during pregnancy and postpartum periods should be prioritized for these vulnerable groups.

The national HIV program should strengthen differentiated service delivery models by expanding multi-month dispensing, community ART delivery, and fast-track refill systems. These approaches can reduce structural barriers to care and improve continuity of treatment among women receiving ART.

Health facilities should improve routine documentation of clinical stability, opportunistic infections, tuberculosis preventive therapy uptake, and patient engagement indicators. Better data quality will improve both patient management and the performance of predictive models.

The Rwanda Biomedical Centre should also establish standard operating procedures for ethical and equitable use of predictive analytics in HIV care. These procedures should define how risk scores are generated, interpreted, and used while ensuring patient confidentiality, minimizing stigma, and promoting fair use of data-driven interventions.

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Original Research

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Prevalence and factors associated with the uptake of the second dose of the measles vaccine among children aged 18–59 months in Rusizi Healthcare Facilities, Rwanda, 2025

Chantal Byukusenge[1], Tefera Tezer[1,*], Abel Karamari[1]

[1]*Department of Public Health, Mount Kenya University, Kigali- Rwanda*

ABSTRACT

INTRODUCTION: Measles remains a major public health challenge despite the availability of safe and effective vaccines. Completion of the second dose of the measles-containing vaccine (MCV2) is essential for achieving herd immunity and preventing outbreaks. This study determined the prevalence of MCV2 uptake and factors associated with its completion among children aged 18–59 months attending healthcare facilities in Rusizi District, Rwanda.

METHODS: A facility-based cross-sectional study was conducted between March and April 2025 among 287 caregivers selected using multistage and systematic random sampling. Data were collected through interviewer-administered questionnaires and vaccination card reviews. Descriptive statistics, chi-square tests, and multivariable logistic regression were performed using SPSS version 27. Adjusted odds ratios (AORs) with 95% confidence intervals (CIs) were used to identify factors associated with MCV2 uptake at $p<0.05$.

RESULTS: MCV2 uptake was 74.9% (215/287), below the WHO target of 95% required for herd immunity. Higher household income was associated with increased vaccine uptake (201,000–300,000 RWF: AOR=2.49, 95% CI: 1.05–5.88; >301,000 RWF: AOR=3.36, 95% CI: 1.37–8.22). High caregiver knowledge also increased the likelihood of MCV2 completion (AOR=2.11, 95% CI: 1.01–4.42). Conversely, living more than 10 km from a health facility, waiting over two hours for services, and inconsistent vaccine availability significantly reduced vaccine uptake.

CONCLUSION: MCV2 uptake in Rusizi District remains below the level required for herd immunity. Strengthening outreach services, improving vaccine availability, reducing waiting times, and enhancing caregiver education are essential to increase MCV2 completion and reduce the risk of measles outbreaks.

***Corresponding author:**
Dr. Tefera Tezera Negera

Department of Public Health, Mount Kenya University, Kigali, Rwanda

Email: teferamulu1987@gmail.com

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INTRODUCTION

Measles is a highly contagious viral disease and remains an important cause of morbidity and mortality among children under five years globally despite the availability of safe and effective vaccines [1]. The disease spreads through respiratory droplets and direct contact with infected individuals and may result in severe complications including pneumonia, encephalitis, diarrhea, blindness, and death, particularly among unvaccinated children [2]. The World Health

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Organization (WHO) recommends administration of two doses of measles-containing vaccine (MCV), with the first dose (MCV1) given at 9 months and the second dose (MCV2) administered at 15–18 months to ensure adequate immunity and herd protection [3].

Globally, substantial progress has been achieved in reducing measles-related deaths through routine immunization programs and supplementary immunization activities. However, measles outbreaks continue to occur in many low- and middle-income countries due to suboptimal vaccination coverage, missed vaccination opportunities, weak healthcare systems, and vaccine hesitancy [4]. In Sub-Saharan Africa, low uptake of MCV2 has remained a public health concern, particularly in rural and underserved populations where healthcare accessibility and vaccine availability remain limited [5].

In Rwanda, the Expanded Program on Immunization (EPI) has significantly improved childhood immunization coverage through strengthened healthcare delivery systems, community health worker involvement, integrated health data systems, mHealth reminders, and nationwide vaccination campaigns [6]. According to the Rwanda Demographic and Health Survey and Ministry of Health reports, MCV1 coverage remains relatively high nationally, but MCV2 coverage has consistently remained lower than the WHO target of 95% in Rusizi district [7]. Recent surveillance reports also indicated periodic measles outbreaks in Western Province and border districts neighboring the Democratic Republic of Congo, including Rusizi District, where cross-border movement and inconsistent immunization uptake may contribute to increased transmission risks [8].

Previous studies conducted in African countries have identified caregiver knowledge, household income, transportation challenges, long waiting times, and vaccine stock-outs as important determinants of childhood immunization completion [5,9]. However, limited evidence exists regarding factors influencing uptake of the second dose of measles vaccine among children aged 18–59 months in Rusizi District. This study therefore aimed to determine the prevalence and factors associated with uptake of the second dose of measles-containing vaccine among children aged 18–59 months attending healthcare facilities in Rusizi District, Rwanda. The study hypothesized that caregiver-related, economic, and institutional factors significantly influence MCV2 uptake.

METHODS

Study Design and Study Area

A facility-based descriptive cross-sectional study was conducted in Rusizi District, Western Province, Rwanda, between March and April 2025. Rusizi District borders the Democratic Republic of Congo and consists of both urban and rural sectors served by public and private healthcare facilities providing routine immunization services. The study design was chosen because it enabled simultaneous assessment of prevalence and associated factors of uptake of the second dose of measles-containing vaccine (MCV2) among children aged 18–59 months.

Study Population

The study population comprised caregivers of children aged 18–59 months attending selected healthcare facilities for child health and immunization services during the study period. The accessible population was identified from immunization clinic attendance records in selected healthcare facilities.

Inclusion and Exclusion Criteria

Caregivers of children aged 18–59 months who attended selected healthcare facilities during the study period and consented to participate were included in the study. Caregivers who were critically ill, unable to communicate effectively, or unwilling to participate were excluded.

Sample Size Determination and Sampling Procedure

The sample size was calculated using Fisher's formula for cross-sectional studies with a 95% confidence level, 5.0% margin of error, and an assumed prevalence of 50.0%. Since the target population was below 10,000, finite population correction was applied, resulting in a final sample size of 287 participants.

A multistage sampling technique was used. In the first stage, healthcare facilities providing routine immunization services in Rusizi District were listed. According to district health records, there were 18 eligible health centers offering routine immunization services in Rusizi District. Health posts and clinics with irregular immunization services were excluded from the sampling frame to ensure consistency in service delivery.

From the 18 eligible health centres, 10 health facilities were selected using simple random sampling (lottery method), ensuring that each facility had an equal probability of selection and that both rural and semi-urban settings were represented. In the second stage, proportional allocation was applied to distribute the total sample size (n = 287) across the 10 selected health facilities based on the average monthly immunization clinic attendance in each facility. This ensured that facilities with higher client flow contributed more participants while maintaining representativeness across all sites.

Within each selected health facility, systematic random sampling was used to recruit eligible caregivers. The sampling interval (k=3) was determined by dividing the estimated number of eligible caregivers attending immunization services during the study period by the allocated sample size per facility. A random starting point between 1 and k was selected, and thereafter every 3th eligible caregiver was recruited until the required sample size per facility was achieved

Data Collection Instrument and Procedure

Data were collected using a structured interviewer-administered questionnaire developed from previous immunization studies and WHO vaccination assessment guidelines [10,11]. The questionnaire contained sections on socio-demographic characteristics, caregiver knowledge, economic factors, and institutional factors associated with MCV2 uptake. Vaccination cards and child health records were reviewed to verify vaccination status and minimize recall bias.

The questionnaire was initially prepared in English and translated into Kinyarwanda for data collection. Trained research assistants conducted face-to-face interviews under supervision of the principal investigator. Daily supervision and verification of completed questionnaires were performed to ensure data completeness and consistency.

Operational Definition of Knowledge Level

Caregiver knowledge regarding measles vaccination was assessed using 10 structured knowledge questions. Each correct response scored one mark, while incorrect or "don't know" responses scored zero. Total scores ranged from 0–10 and were categorized as follows: Low knowledge: 0–4 points; moderate knowledge: 5–7 points; and high knowledge: 8–10 points.

Validity and Reliability

Content validity of the instrument was assessed by public health and epidemiology experts to ensure relevance and clarity of questionnaire items. The questionnaire was pretested among 28 caregivers at Mugonero Health Facility in Nyamasheke District, which was not included in the main study. Reliability was assessed using Cronbach's alpha coefficient, and the tool demonstrated good internal consistency with a Cronbach's alpha value of 0.82.

Data Quality Control

Research assistants received one-day training on study objectives, ethical principles, interview techniques, and questionnaire administration. Completed questionnaires were checked daily for completeness and accuracy. Vaccination cards were used where available to reduce information and recall bias. Confidentiality was maintained through use of unique identification codes instead of participant names.

Data Management and Statistical Analysis

Collected data were coded, cleaned, and entered into Statistical Package for Social Sciences (SPSS) version 26 for analysis. Descriptive statistics including frequencies, percentages, means, and standard deviations were used to summarize study variables. Bivariate analysis using chi-square tests was performed to determine associations between independent variables and MCV2 uptake.

Variables with p-values less than 0.05 at bivariate analysis were included in multivariate logistic regression analysis to identify independent predictors of MCV2 uptake. Adjusted Odds Ratios (AORs) with 95.0% Confidence Intervals (CIs) were reported. Caregiver age and education level were additionally included in the multivariate model to control for confounding effects. Interaction between distance to healthcare facility and transport cost was assessed during regression modeling. Multicollinearity among predictor variables was assessed using Variance Inflation Factor (VIF), and no significant multicollinearity was identified (all VIF values <2.5). Model fitness was assessed using the Hosmer–Lemeshow goodness-of-fit test (p=0.71), indicating adequate model fit.

Ethical Considerations

Ethical approval was obtained from the Mount

Kenya University Research Ethics Committee (Approval No: MKU/PH/2025/041). Permission to conduct the study was also obtained from Rusizi District health authorities and participating healthcare facilities. Written informed consent was obtained from all participants before data collection. Participation was voluntary, and respondents were informed of their right to withdraw from the study at any time without penalty. Confidentiality and anonymity were maintained throughout the study.

RESULTS

A total of 287 caregivers of children aged 18–59 months participated in the study, giving a response rate of 100.0%. No participant withdrew from the study, and there were no incomplete questionnaires or missing records during data collection.

Socio-demographic Characteristics of Respondents

Most caregivers were aged 20–29 years (41.5%), followed by 30–39 years (28.6%). Female caregivers constituted the majority (72.5%). Most respondents were married (74.2%), and more than half had secondary education (55.1%).

Table 1: *Socio-demographic characteristics of respondents*

Characteristics/Categories	Frequency n (%)
Caregiver age	
<20 years	59 (20.6)
20–29 years	119 (41.5)
30–39 years	82 (28.6)
≥40 years	27 (9.4)
Gender	
Male	79 (27.5)
Female	208 (72.5)
Marital status	
Single	59 (20.6)
Married	213 (74.2)
Widowed	8 (2.8)
Divorced/Separated	7 (2.4)
Education level	
No formal education	14 (4.9)
Primary education	60 (20.9)
Secondary education	158 (55.1)
Higher education	55 (19.2)

Self-employment (36.6%) and farming (26.1%) were the most common occupations among caregivers.

Prevalence of Uptake of the Second Dose of Measles Vaccine

The overall prevalence of uptake of the second dose of measles-containing vaccine (MCV2) among children aged 18–59 months was 74.9% (215/287), while 25.1% (72/287) had not received the second dose (Table 2).

Caregiver Knowledge Regarding Measles Vaccination

Assessment of caregiver knowledge showed that 64.8% had moderate knowledge, 32.1% had low knowledge, and only 3.1% demonstrated high knowledge regarding measles vaccination and immunization schedules (Table 3).

Economic Factors Associated with MCV2 Uptake

Children from households earning more than 301,000 RWF per month were more likely to receive MCV2 compared to those earning less than 100,000 RWF (COR = 1.841; 95% CI: 0.867–3.906; p = 0.012), Vaccination-related costs were negatively associated with uptake, where spending 2,000–5,000 RWF (COR = 0.292; 95% CI: 0.137–0.621; p = 0.001) and ≥5,000 RWF (COR = 0.318; 95% CI: 0.140–0.722; p = 0.006) reduced the likelihood of completing MCV2. In addition, children living more than 10 km from a health facility had higher odds of MCV2 uptake

Table 2: *Uptake of the Second Dose of Measles Vaccine*

Variable	Frequency n (%)
MCV2 uptake	
Yes	215 (74.9)
No	72 (25.1)
Total	287 (100)

Table 3: *Caregiver Knowledge Levels on Measles Vaccination*

Variable	Frequency n (%)
Knowledge level	
Low knowledge	92 (32.1)
Moderate knowledge	186 (64.8)
High knowledge	9 (3.1)

Knowledge scores were categorized based on responses to 10 knowledge assessment questions.

compared to those within 1 km (COR = 2.600; 95% CI: 1.021–6.619; p = 0.045), Children of caregivers with moderate knowledge had higher odds of receiving MCV2 compared to those with low knowledge (COR = 1.78; 95% CI: 1.05–3.02; p = 0.033). Similarly, caregivers with high knowledge were more likely to complete MCV2 vaccination for their children (COR = 2.64; 95% CI: 1.10–6.32; p = 0.028) (Table 4).

Multivariate logistic regression analysis identified household income and transport costs as significant predictors of MCV2 uptake. Children from households earning 201,000–300,000 RWF were more likely to receive MCV2 compared to households earning less than 100,000 RWF (AOR=2.49; 95.0% CI:1.05–5.88; p=0.038). Similarly, children from households earning above 301,000 RWF had increased odds of MCV2 uptake (AOR=3.36; 95.0% CI:1.37–8.22; p=0.008). Children whose caregivers spent between 2,000–5,000 RWF on transportation were less likely to receive MCV2 (AOR=0.31; 95.0% CI:0.14–0.68; p=0.004). In addition, children living more than 10 km from healthcare facilities had significantly higher odds of missing MCV2 vaccination compared to those living within 1 km (AOR=4.70; 95.0% CI:1.60–13.83; p=0.005). Children of caregivers with high knowledge had higher odds of MCV2 uptake compared to those with low knowledge (AOR = 2.11; 95% CI: 1.01–4.42; p = 0.047) (Table 5).

Institutional Factors Associated with MCV2 Uptake

The bivariate analysis showed that several institutional factors were significantly associated with uptake of MCV2. Longer distance to health

Table 4: *Bivariate logistic regression analysis of economic factors associated with uptake of the second dose of measles vaccine*

Variable	Category	COR (95% CI)	P-value
Household Income	<100,000 RWF	Ref	–
	100,000–200,000 RWF	1.116 (0.527–2.365)	0.774
	201,000–300,000 RWF	1.342 (0.647–2.783)	0.429
	>301,000 RWF	1.841 (0.867–3.906)	0.012
Health Insurance	No	Ref	–
	Yes	1.602 (0.774–3.314)	0.204
Mode of Transport	Walking	Ref	–
	Public	1.583 (0.806–3.110)	0.182
	Private	1.150 (0.544–2.430)	0.715
Vaccination Cost	Nothing	Ref	–
	<2,000 RWF	0.608 (0.302–1.222)	0.162
	2,000–5,000 RWF	0.292 (0.137–0.621)	**0.001**
	≥5,000 RWF	0.318 (0.140–0.722)	**0.006**
Transport Affordability	Easily	Ref	–
	With difficulty	1.530 (0.814–2.877)	0.186
	Not easy	0.970 (0.474–1.987)	0.934
Distance to Facility	<1 km	Ref	–
	1–5 km	1.083 (0.610–1.925)	0.785
	6–10 km	0.773 (0.241–2.474)	0.664
	>10 km	2.600 (1.021–6.619)	**0.045**
Caregiver Knowledge Level	Low knowledge	Ref	–
	Moderate knowledge	1.78 (1.05–3.02)	**0.033**
	High knowledge	2.64 (1.10–6.32)	**0.028**

COR = Crude Odds Ratio; CI = Confidence Interval; Ref = Reference category; RWF = Rwandan Francs; p-value indicates statistical significance, with p < 0.05 considered significant.

Table 5: *Multivariate analysis of economic factors associated with the uptake of measles vaccine*

Variables	Category	AOR (95% CI)	p-value
Household income	<100,000 RWF	Ref	–
	201,000–300,000 RWF	2.49 (1.05–5.88)	0.038
	>301,000 RWF	3.36 (1.37–8.22)	0.008
Transport cost	None	Ref	–
	2,000–5,000 RWF	0.31 (0.14–0.68)	0.004
Distance to facility	<1 km	Ref	–
	>10 km	4.70 (1.60–13.83)	0.005
Caregiver knowledge level	Low knowledge	Ref	–
	Moderate knowledge	1.62 (0.92–2.88)	0.091
	High knowledge	2.11 (1.01–4.42)	**0.047**

AOR: Adjusted Odds Ratio; CI: Confidence Interval; Ref: Reference category.

facilities, prolonged waiting time, and inconsistent vaccine availability were significantly associated with reduced likelihood of MCV2 uptake at the crude level (Table 6).

In multivariate analysis, institutional factors including distance to healthcare facilities, waiting time, and vaccine availability significantly influenced uptake of MCV2. Children living more

Table 5: *Bivariate analysis of institutional factors associated with the uptake of measles vaccine*

Variable	Category	COR (95% CI)	p-value
Distance to health facility	<1 km	Ref	–
	1–5 km	1.47 (0.43–4.99)	0.54
	6–10 km	0.77 (0.24–2.47)	0.664
	>10 km	0.11 (0.03–0.43)	**<0.001**
Waiting time at facility	<30 min	Ref	–
	30–60 min	0.68 (0.28–1.62)	0.38
	1–2 hrs	0.38 (0.17–0.87)	0.022
	>2 hrs	0.17 (0.07–0.41)	**<0.001**
Vaccine stock-out	No	Ref	–
	Yes	0.64 (0.37–1.12)	0.117
Healthcare workers' attitude	Very friendly	Ref	–
	Neutral	1.01 (0.51–1.99)	0.979
	Unfriendly	1.81 (0.82–3.98)	0.143
Vaccine availability	Always	Ref	–
	Sometimes	1.03 (0.54–1.95)	0.935
	Rarely	2.15 (0.57–8.13)	**0.05**
	Don't know	0.65 (0.25–1.64)	0.358
Facility satisfaction	Very satisfied	Ref	–
	Somewhat satisfied	0.68 (0.30–1.54)	0.356
	Neutral	0.78 (0.32–1.90)	0.579
	Dissatisfied	0.69 (0.18–2.67)	0.589

COR = Crude Odds Ratio; CI = Confidence Interval; Ref = Reference category; p-value < 0.05 considered significant.

Table 5: *Multivariate Analysis of institutional factors associated with the uptake of measles vaccine*

Variables	AOR (95% CI)	p-value
Distance to health facility		
• <1 km	Ref	–
• >10 km	0.08 (0.02–0.37)	**<0.001**
Waiting time at facility		
• <30 minutes	Ref	–
• >2 hours	0.30 (0.11–0.84)	**0.022**
Vaccine availability		
• Always available	Ref	–
• Rarely available	0.13 (0.02–0.79)	**0.027**

AOR: Adjusted Odds Ratio; CI: Confidence Interval; Ref: Reference category.

than 10 km from health facilities were significantly less likely to receive MCV2 compared to those living within 1 km (AOR=0.08; 95.0% CI:0.02–0.37; p<0.001). Caregivers who waited more than two hours at healthcare facilities were also less likely to complete MCV2 vaccination (AOR=0.30; 95.0% CI:0.11–0.84; p=0.022). Furthermore, inconsistent vaccine availability significantly reduced vaccine uptake. Children attending facilities where vaccines were rarely available had lower odds of receiving MCV2 compared to facilities with consistent vaccine availability (AOR=0.13; 95.0% CI:0.02–0.79; p=0.027) (Table 7).

DISCUSSION

This study found that MCV2 uptake among children aged 18–59 months in Rusizi District was 74.9%, which remains below the WHO-recommended 95% threshold required for herd immunity. This indicates that a considerable proportion of children are still not fully protected against measles, leaving communities at risk of outbreaks. Similar suboptimal coverage has been reported in Uganda and Kenya, where MCV2 uptake remains below optimal levels despite strong national immunization programs [23,24]. The findings suggest that improving second-dose completion remains a persistent challenge across several East African settings.

In the Rwandan context, this coverage level is lower than national targets reported in routine immunization performance reviews, where MCV2 coverage has generally been estimated above 85% in recent years, although still below the 95% elimination threshold required for measles control. According to the Rwanda Demographic and Health Survey (RDHS 2019–20), full immunization coverage among children aged 12–23 months was relatively high, but dropout between MCV1 and MCV2 remains a documented concern, particularly in western districts such as Rusizi, Nyamasheke, and Rubavu, where geographic access challenges persist [25]. Similarly, the Rwanda EPI annual reports highlight that while MCV1 consistently achieves high coverage nationally, MCV2 uptake lags behind due to missed opportunities, delayed follow-up visits, and caregiver mobility [26]. These patterns suggest that the Rusizi findings are consistent with national evidence of a persistent MCV2 completion gap despite strong first-dose performance.

Most caregivers had moderate knowledge, with few demonstrating high knowledge of measles vaccination schedules. This pattern is consistent with findings from Ethiopia and Kenya, where limited caregiver understanding contributes to incomplete vaccination schedules [27,28]. However, knowledge alone was insufficient to ensure full vaccine uptake, indicating that structural barriers may outweigh behavioral awareness in determining vaccination completion.

This finding is also consistent with Rwanda-based studies conducted in southern and western provinces, which report that although caregiver awareness of routine immunization is generally

high, knowledge gaps persist specifically regarding vaccination schedules, especially the timing of second doses such as MCV2 [27]. The RDHS also indicates that maternal education and exposure to health information through community health workers (CHWs) are strongly associated with full immunization completion, suggesting that knowledge interacts with service accessibility rather than independently determining uptake [25]. Therefore, even in settings like Rwanda where immunization awareness campaigns are widespread, knowledge alone does not fully translate into timely completion of MCV2.

Household income and transport-related costs were significant predictors of MCV2 uptake. Children from higher-income households were more likely to complete vaccination, while those facing higher transport costs had reduced uptake. These findings align with evidence from Ghana, Bangladesh, and other low-income settings where indirect costs such as transport and opportunity costs reduce immunization completion [29,31]. Although vaccines are provided free of charge in Rwanda, indirect financial barriers continue to influence access. This suggests that financial protection strategies targeting indirect costs may be important to improve equity in immunization coverage.

In Rwanda, similar socioeconomic gradients have been documented in immunization uptake. RDHS findings show that children from the lowest wealth quintiles are more likely to experience delayed or incomplete vaccination compared to those from wealthier households, despite nationwide insurance coverage (Mutuelle de Santé) reducing direct cost barriers [25]. In addition, EPI monitoring reports indicate that transport costs and opportunity costs (such as lost working time for caregivers) remain key reasons for missed vaccination appointments, particularly in rural and hard-to-reach sectors of Rusizi District [26]. This suggests that even in a context of free immunization services, economic constraints remain a hidden but significant determinant of MCV2 completion, reinforcing the need for decentralized outreach services and strengthened community-based vaccination strategies.

Institutional factors such as distance to health facilities, waiting time, and vaccine availability were strongly associated with MCV2 uptake. Children living farther from health facilities and those experiencing long waiting times were less likely to complete vaccination. Similar findings have been reported in Uganda and Nigeria, where geographical inaccessibility and long service delays reduce immunization adherence [35,36]. Vaccine stock-outs and inconsistent availability also negatively affected uptake, consistent with studies in East Africa highlighting supply chain weaknesses as a major barrier to vaccination completion [36]. These findings underscore the importance of strengthening service delivery systems and improving vaccine logistics.

In Rwanda, these institutional barriers are particularly relevant in rural and island-adjacent sectors of Rusizi, where terrain and distance to health centers significantly affect service utilization. The RDHS and EPI reports consistently highlight geographic inequities in health service access, with western provinces reporting higher rates of missed immunization appointments compared to urban districts such as Kigali [25,26]. Furthermore, Rwanda's Health Management Information System (HMIS) reports indicate that while national vaccine stock-out rates are generally low, sub-national disparities still occur due to cold-chain limitations and distribution inefficiencies at health center level, which can temporarily disrupt MCV2 service delivery [26]. Studies conducted in Rwandan border districts have also shown that long waiting times and opportunity costs discourage return visits for second-dose vaccines, contributing directly to dropout between MCV1 and MCV2 [27]. These findings emphasize that improving immunization completion requires not only demand-side interventions but also continued strengthening of supply chain efficiency and service delivery responsiveness.

The findings highlight the need for integrated immunization strategies that address both demand- and supply-side barriers. Strengthening community outreach, improving health facility efficiency, and ensuring consistent vaccine availability could significantly improve MCV2 coverage in Rusizi District. Additionally, enhancing caregiver education through community health workers may help improve adherence to vaccination schedules.

This study was cross-sectional in design, which

limits the ability to establish causal relationships between the independent variables and MCV2 uptake among children. Therefore, the associations observed should be interpreted as correlational rather than causal. There is also a possibility of recall bias, particularly among caregivers who were unable to accurately remember vaccination histories. However, this limitation was minimized by cross-checking responses with child vaccination cards whenever they were available.

In addition, the study employed a facility-based sampling approach, which may have introduced selection bias. Specifically, caregivers who attended health facilities were more likely to be included in the study, while those who do not routinely seek healthcare services may have been systematically excluded. This could result in overrepresentation of health-seeking caregivers, who may differ in knowledge, attitudes, and vaccination practices compared to those not accessing health services. As a result, the findings may not be fully generalizable to the entire population of caregivers in the community.

Social desirability bias may also have influenced responses, as caregivers might have provided answers they perceived as acceptable to health workers or researchers, particularly regarding vaccination practices and child health behaviors.

CONCLUSION

The uptake of the second dose of the measles-containing vaccine (MCV2) among children aged 18–59 months in Rusizi District was 74.9%, below the WHO-recommended 95% threshold for herd immunity. Uptake was influenced by socioeconomic, caregiver, and health system factors. Higher household income and better caregiver knowledge significantly increased the likelihood of completing MCV2, whereas long travel distances, prolonged waiting times, and inconsistent vaccine availability reduced vaccine uptake. These findings highlight the need for integrated interventions to improve immunization completion. The Ministry of Health and Rusizi District should expand outreach and mobile vaccination services in underserved communities, strengthen vaccine supply chain management to eliminate stock-outs, reduce waiting times through improved staffing and appointment systems, and enhance caregiver education on the importance of completing the two-dose schedule. Community health workers should intensify defaulter tracing and reminder systems using routine EPI, integrated Civil Registration and Vital Statistics (CRVS) and HMIS data to identify children who miss scheduled vaccinations. These coordinated strategies will improve MCV2 coverage, reduce missed opportunities for vaccination, and support Rwanda's progress toward measles elimination.

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Original Research

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Healthcare providers' practices, facilitators, and challenges in early intervention service delivery for children with developmental delays at the University Teaching Hospital of Kigali (CHUK)

Celestin Bigirimana[1,*], Potien Uwihoreye[2], Joseph Nshimiyimana[2], Joanitah Kemigisha[3], Gashugi Phophina[4], Cecile Mukakimenyi Gahamanyi[5], Angelique Gakuru[6]

[1]*Department of Occupational Therapy, University Teaching Hospital of Kigali, Kigali, Rwanda*
[2]*Department of Occupational Therapy, University of Rwanda, Kigali, Rwanda*
[3]*Department of Physiotherapy, University of Rwanda, Kigali, Rwanda*
[4]*Department of Physiotherapy, University Teaching Hospital of Kigali, Kigali, Rwanda*
[5]*Department of Physiotherapy, Rwanda Military Teaching Hospital, Kigali, Rwanda*
[6]*Department of Pediatrics Neurology, University Teaching Hospital of Kigali, Kigali, Rwanda*

***Corresponding author:**
Celestin Bigirimana

Department of Occupational Therapy, University Teaching Hospital of Kigali, Kigali, Rwanda

Email: bigicelestino2@gmail.com

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ABSTRACT

INTRODUCTION: Early intervention (EI) is critical for improving developmental outcomes among children at risk of developmental delays, yet implementation in low- and middle-income countries remains constrained. This study assessed healthcare provider practices, facilitators, and barriers to EI service delivery at the University Teaching Hospital of Kigali (CHUK).

METHODS: A facility-based cross-sectional study was conducted among 108 healthcare providers involved in pediatrics and rehabilitation services. Data were collected using structured questionnaires administered via Kobo Toolbox, capturing developmental screening practices, referral systems, facilitators, and perceived challenges. Descriptive statistics and chi-square tests were used to examine associations between provider characteristics and EI practices

RESULTS: Routine developmental monitoring was moderately implemented, with 49.1% of providers consistently assessing developmental milestones and 33.3% incorporating caregiver education. However, major gaps were identified in structured EI systems: 42.6% reported limited use of standardized screening tools, 64.8% lacked confidence in referral, and 66.7% reported absence of clear referral pathways. Key facilitators included multidisciplinary teamwork (60.2%), access to assistive devices (64.8%), and staff training or mentorship (50.9%). Major barriers included inadequate rehabilitation infrastructure (55.6%), limited outreach services (75.9%), insufficient trained personnel, and low caregiver awareness. No significant associations were observed between provider socio-demographic characteristics.

CONCLUSION: While foundational EI practices exist at CHUK, critical weaknesses in screening, referral systems, and service integration limit effective implementation. Strengthening standardized screening, referral pathways, provider capacity, and community outreach is essential to improve early identification and equitable access to EI services in Rwanda.

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INTRODUCTION

Early childhood is a period of unparalleled neuroplasticity; global reports emphasize that developmental disabilities are common, under recognized, and poorly integrated into health systems planning [1]. The World Health Organization (WHO) and the United Nations Children's Fund calls for intentional inclusion of children with developmental disabilities in policy, programming and monitoring because these children face persistent barriers to health, education and social participation [2,3]. Recent global analyses estimate substantial regional variation in childhood disability prevalence and highlight that children in low and middle income countries (LMICs) bear a disproportionate burden of risk for not reaching developmental potential due to poverty, malnutrition and perinatal complications [4]. Population level syntheses show that reliable surveillance and routine screening remain limited across many regions, undermining early detection and timely referral [5]. Tertiary hospitals in LMICs, including University Teaching Hospital of Kigali (CHUK), function as referral hubs for complex pediatric care but often retain a pathology oriented culture that prioritizes acute management over longitudinal developmental surveillance and family centered rehabilitation [6]. Implementation reports and program documents stress that aligning provider practice with system design is necessary to close the gap between policy commitments and outcomes. "The first five years of life are characterized by rapid neural connection formation, with more than one million new connections occurring every second[2]. Globally, one in ten children lives with a disability, and in low- and middle-income countries like Rwanda, approximately 43% to 44% of children are at risk of not reaching their developmental potential due to poverty, malnutrition, and medical risks [6].

Socioeconomic constraints (transport costs, caregiver time, limited insurance), health system factors (unclear referral pathways, workforce shortages, lack of decentralized follow up), and cultural stigma jointly reduce families' ability to sustain repeated therapy contacts [2]. Global guidance and regional studies recommend integrated models, routine surveillance, standardized referral algorithms, task sharing with community health workers, and caregiver led interventions, to preserve intervention "dose" and expand reach in resource constrained settings [7]. To convert global commitments into measurable developmental gains, tertiary hospitals must reorient provider workflows toward routine developmental surveillance, formalized referral pathways, and family centered, decentralized follow up actions that are both evidence aligned and feasible within LMIC health systems [8]. Providers (nurses, pediatricians, physiotherapists, occupational therapists and other rehabilitation staff) are the linchpin of early intervention (EI) pathways: their routine behaviors determine early detection, timely referral, and caregiver coaching; all prerequisites for maintaining the therapeutic intensity required for functional gains [9]. Strengthening provider competence in validated screening tools, referral navigation, and family centered counseling is therefore a high leverage strategy to improve population outcomes [9,10]. For occupational therapists and allied health professionals, these contextual realities have direct implications for practice. Effective EI in resource constrained tertiary settings depends on integrating routine developmental surveillance into clinical workflows, standardizing referral algorithms that link hospital based care with community and primary level services, and adapting interventions to reduce travel burden through caregiver coaching, task sharing, and community health worker partnerships [11]. Strengthening provider training in validated screening tools and referral navigation, and embedding family centered approaches into routine care, are practical levers that can improve early detection and sustain engagement.

METHODS

Study Design and Setting

This study employed a cross-sectional quantitative design at the University Teaching Hospital of Kigali (CHUK), focusing on the Pediatric and Functional Rehabilitation departments.

Participants and Sample Size

The study involved healthcare providers working within the Pediatric Department and Functional Rehabilitation Department at CHUK. A census sampling approach was employed whereby all eligible healthcare providers who had worked in their respective departments for at least six months were invited to participate [12]. Because the study sought to include the entire accessible population

of healthcare providers involved in pediatric and rehabilitation services during the study period, no formal sample size calculation was performed. A total of 108 healthcare providers met the eligibility criteria and participated in the study.

Instrumentation Tools

Three structured questionnaires were developed based on existing literature and international early intervention guidelines. The Current Practice Assessment Questionnaire (CPAQ) consisted of 10 items assessing developmental surveillance activities, developmental screening practices, referral procedures, developmental monitoring, caregiver education, and provider training. Responses were measured on a four-point Likert scale ranging from "Always" to "Rarely/Never."

The Challenges and Facilitators Identification Questionnaire (CFIQ) comprised 16 items divided into two domains: facilitators of early intervention implementation (8 items) and perceived implementation challenges (8 items). Responses were measured using a three-point scale (Agree/ Strongly Agree, Neutral, Disagree/Strongly Disagree). The Early Intervention Benefits Assessment Questionnaire (EIBAQ) explored providers' perceptions regarding the contribution of early intervention services to developmental care and family support. Because objective child outcomes were not measured, responses reflected provider perceptions rather than direct developmental outcomes.

Questionnaire content validity was established through review by experts in pediatrics, rehabilitation, occupational therapy, and research methodology. A pilot study conducted at King Faisal Hospital Rwanda and Rwanda Military Teaching Hospital demonstrated good internal consistency reliability, with a Cronbach's alpha coefficient of 0.89. Data were collected electronically using Kobo Toolbox between November 9th and December 9th, 2025.

Data Analysis

Data collected through Kobo Toolbox were exported to IBM SPSS Statistics version 29.0 for analysis. Data were checked for completeness, consistency, and missing values prior to analysis. Descriptive statistics including frequencies, percentages, means, and standard deviations were used to summarize healthcare providers' socio-demographic characteristics, developmental screening practices, facilitators of early intervention implementation, and perceived challenges.

Pearson's chi-square tests were conducted to examine associations between socio-demographic characteristics (age, gender, marital status, profession, and work experience) and selected early intervention practice variables. Additional analyses explored relationships between developmental surveillance training, use of standardized developmental screening tools, referral confidence, referral pathway availability, and professional cadre. The strength of associations was assessed using Cramér's V. Statistical significance was set at $p < 0.05$.

Ethical Considerations

Ethical approval was granted by the CHUK Institutional Review Board (Ref.: EC/ CHUK/170/2025), and all participants provided informed consent prior to data collection.

Funding

The study obtained a financial support for data collection and analysis through CHUK small Grant's scheme No EC/CHUK/170/2025

RESULTS

Socio-Demographic Profile of Healthcare Providers

In the current study a total of 108 healthcare providers participated in the study at CHUK, representing a predominantly young to middle-aged and female-led workforce. Nearly half of the participants (47.2%) were aged 31–40 years. The professional distribution showed that nurses constitute the largest proportion of the EI workforce at 64.81%, followed by physiotherapists (11.11%). Smaller representations were found for medical pediatricians (5.56%), occupational therapists (5.56%), psychologists (4.63%), and nutritionists (2.78%) (Table 1).

Developmental Screening and Clinical Practices

Early intervention practices showed a mixed pattern across respondents in table 4.2. Routine clinical practices such as developmental milestone assessments were relatively well implemented, with nearly half of participants reporting they always conduct them (49.1%; mean = 2.11, SD = 1.10), and caregiver education was also commonly

Table 1: *Socio-Demographic Profile of Healthcare Providers*

Variables	Frequency, n (%)	Mean (SD)
Age		2.16(1.02)
20–30	25(23.14)	
31–40	51(47.2)	
41–50	24(22.2)	
50 and above	8(7.4)	
Gender		2.47(0.90)
Male	24(22.22)	
Female	84(77.77)	
Marital status		3.71(0.96)
Single	33 (30.55)	
Married	75(69.44)	
Department/profession		3.4(0.79)
Nurses	70(64.81)	
Physiotherapy	12(11.11)	
Occupational Therapy	6(5.56)	
Medical pediatric Doctors	6(5.56)	
Prosthetics & Orthotics	3(2.78)	
Human Nutrition	3(2.78)	
Social Workers	2(1.85)	
Psychologists	5(4.63)	
Audiology	1(0.93)	
Working experience		1.47(1.79)
6 months–1 year	19(17.6)	
1–2 years	21(19.44)	
>2 years	68(62.9)	

integrated into care (33.3% always; mean = 2.20, SD = 0.97). However, critical components of structured early intervention systems were notably weak. The majority of respondents reported rarely or never having confidence in referring children (64.8%; mean = 3.43, SD = 1.20) or access to clear referral pathways (66.7%; mean = 3.40, SD = 1.32). Similarly, the use of standardized developmental screening tools was limited, with 42.6% reporting rare or no use (mean = 2.94, SD = 1.24). Training in developmental surveillance was inconsistent, and access to contextually appropriate tools was moderate (Table 2).

Facilitators of Early Intervention Implementation

Facilitators of early intervention implementation showed a varied pattern, with some system strengths alongside notable gaps in the table 4.3. Strong facilitators included access to assistive devices (64.8% agreement; mean = 1.48, SD = 1.38), multidisciplinary teamwork (60.2%; mean = 1.56, SD = 1.40), and staff training or mentorship (50.9%; mean = 1.67, SD = 1.37), indicating that structural and professional support mechanisms are relatively established. However, several key facilitators were weak or inconsistent. A substantial proportion of respondents disagreed that rehabilitation spaces and equipment were adequate (55.6%; mean = 2.31, SD = 1.40) and that outreach programs were available (75.9%; mean = 2.65, SD = 1.29), highlighting major infrastructural and community-level gaps. Caregiver involvement was also limited, with nearly half of participants expressing disagreement (49.1%; mean = 2.33, SD = 1.29). Referral pathways and home-based

Table 2: *Developmental Screening and Early Intervention Clinical Practices among Healthcare Providers (n = 108)*

Variables	Always	Sometimes	Often	Rarely/ Never	Mean (SD)
Screening less than five years for developmental delays	22(20.4)	48(44.4)	24(22.2)	14(13.0)	2.28(0.99)
Use developmental screening tools (questionnaires, checklists)	10(9.3)	36(33.3)	17(15.7)	46(42.6)	2.94(1.24)
Early intervention includes caregiver education or training	36(33.3)	34(31.5)	22(20.4)	17(15.7)	2.20(0.97)
Confidence in referring children with developmental concerns to EI services	5(4.6)	17(15.7)	17(15.7)	70(64.8)	3.43(1.20)
Referral pathway clearly available when concerns identified	5(4.6)	22(20.4)	10(9.3)	72(66.7)	3.40(1.32)
Received training in developmental surveillance and screening	24(22.2)	41(38.0)	19(17.6)	24(22.2)	2.40(1.29)
Access to contextual appropriate assessment tools	26(24.1)	5(4.6)	50(46.3)	26(24.1)	2.69(1.19)
Developmental milestone assessments for children at risk	53(49.1)	14(13.0)	17(15.7)	24(22.2)	2.11(1.10)
Monitoring growth for children at risk of developmental delay	17(15.7)	38(35.2)	31(28.7)	22(20.4)	2.54(1.54)
Use of Kangaroo Mother Care (KMC) for infants with developmental risks	10(9.3)	36(33.3)	31(28.7)	31(28.7)	2.77(1.03)

SD: Standard deviation

strategies showed mixed responses (Table 3).

Perceived challenges of Early Intervention Implementation

Perceived challenges to early intervention implementation reveal important system and community-level constraints in the table 4.4. While about half of respondents agreed that initial-contact providers routinely screen at-risk children (50.9%; mean = 1.82, SD = 1.50), concerns remain regarding workforce capacity, with only 39.8% agreeing that there are enough trained early intervention specialists (mean = 1.94, SD = 1.59). Referral systems also appear inconsistent,

Table 3: *Facilitators of Early Intervention Implementation*

Variables	Agree / Strongly Agree	Neutral	Disagree / Strongly Disagree	Mean (SD)
Multidisciplinary team	65(60.2)	26(24.1)	17(15.7)	1.56(1.40)
Staff training / mentorship	55(50.9)	34(31.5)	19(17.6)	1.67(1.37)
Caregiver involvement	17(15.7)	38(35.2)	53(49.1)	2.33(1.29)
Home-based strategies	36(33.3)	31(28.7)	41(38.0)	2.05(1.58)
Rehab spaces / equipment	26(24.1)	22(20.4)	60(55.6)	2.31(1.40)
Assistive devices access	70(64.8)	24(22.2)	14(13.0)	1.48(1.38)
Outreach programs	12(11.1)	14(13.0)	82(75.9)	2.65(1.29)
Referral pathways	38(35.2)	34(31.5)	36(33.3)	1.98(1.54)

SD: Standard deviation

Table 4: *Perceived challenges of Early Intervention Implementation*

Variables	Agree/ Strongly Agree (%)	Neutral (%)	Disagree/ Strongly Disagree (%)	Mean (SD)
Enough trained early intervention specialists on staff	43(39.8)	29(26.9)	36(33.3)	1.94(1.59)
Initial-contact providers routinely screen at-risk children	55(50.9)	17(15.7)	36(33.3)	1.82(1.50)
Parents/caregivers are well informed about early signs	26(24.1)	26(24.1)	55(51.0)	2.25(1.59)
Cultural beliefs or stigma discourage caregivers from seeking EI	26(24.1)	26(24.1)	55(51.0)	2.25(1.48)
Clear formal referral pathway between hospital and community services	43(39.8)	31(28.7)	34(31.5)	1.92(1.52)

SD: Standard deviation

Table 3: *Associations between Socio-Demographic Characteristics and Early Intervention Practices and Perceived Challenges*

Variables	Frequency, n (%)	χ^2 (df)	p	Cramér's V
Age (years)		5.67 (6)	0.458	0.1
20–30	25 (23.1)			
31–40	51 (47.2)			
41–50	24 (22.2)			
≥50	8 (7.4)			
Gender		4.12 (2)	0.127	0.12
Male	24 (22.2)			
Female	84 (77.8)			
Marital status		1.84 (2)	0.398	0.08
Single	33 (30.6)			
Married	75 (69.4)			
Department/Profession		16.45 (18)	0.58	0.09
Nurses	70 (64.8)			
Physiotherapy	12 (11.1)			
Occupational Therapy	6 (5.6)			
Pediatric Doctors	6 (5.6)			
Prosthetics & Orthotics	3 (2.8)			
Human Nutrition	3 (2.8)			
Social Workers	2 (1.9)			
Psychologists	5 (4.6)			
Audiology	1 (0.9)			
Work experience		3.77 (4)	0.438	0.08
6 months–1 year	19 (17.6)			
1–2 years	21 (19.4)			
>2 years	68 (62.9)			

χ^2: Pearson's Chi-square statistic; df: degrees of freedom. Statistical significance was set at $p < 0.05$.

as opinions were divided on the existence of clear formal referral pathways (39.8% agree vs. 31.5% disagree; mean = 1.92, SD = 1.52). Notably, caregiver-related factors emerged as significant challenges: a majority of respondents disagreed that parents are well informed about early developmental signs (51.0%; mean = 2.25, SD = 1.59), and similarly rejected the influence of cultural beliefs or stigma (51.0%; mean = 2.25, SD = 1.48) (Table 4).

Associations between Socio-Demographic Characteristics and Early Intervention Practices and Perceived Challenges

In relation to the study objective of examining whether socio-demographic characteristics influence early intervention practices and perceived challenges in the table 4.5 below, the findings indicated that such characteristics do not play a statistically significant role. The study sample (n = 108) was largely composed of participants aged 31–40 years (47.2%), females (77.8%), and married individuals (69.4%), with the majority working as nurses (64.8%) and having more than two years of professional experience (62.9%).

Chi-square analysis revealed no statistically significant associations between socio-demographic variables and early intervention outcomes. Specifically, gender ($\chi^2(2) = 4.12$, $p = 0.127$, Cramér's $V = 0.12$), age ($\chi^2(6) = 5.67$, $p = 0.458$, $V = 0.10$), marital status ($\chi^2(2) = 1.84$, $p = 0.398$, $V = 0.08$), department ($\chi^2(18) = 16.45$, $p = 0.580$, $V = 0.09$), and work experience ($\chi^2(4) = 3.77$, $p = 0.438$, $V = 0.08$) were not significantly associated with early intervention practices or perceived challenges (Table 5).

Factors Associated with Early Intervention Practices among Healthcare Providers

Additional analyses were conducted to explore factors associated with early intervention practices among healthcare providers 6. Significant associations were observed between developmental surveillance training and the use of developmental screening tools ($\chi^2(16) = 23.23$, $p = 0.002$), referral confidence ($\chi^2(16) = 19.22$, $p = 0.027$), referral pathway availability ($\chi^2(16) = 24.78$, $p = 0.044$), and access to contextual assessment tools ($\chi^2(12) = 16.67$, $p = 0.002$). The use of standardized developmental assessment tools was also significantly associated with department/unit ($\chi^2(18) = 30.61$, $p = 0.001$). No statistically significant associations were found between working experience and the use of developmental screening tools, referral confidence, or referral pathway availability, nor between profession/area of specialization and access to adequate early intervention resources ($p > 0.05$) (Table 6).

Table 6: *Factors Associated with Early Intervention Practices among Healthcare Providers*

Variable	χ^2(df)	p
Use of developmental screening tools × Working experience	11.47(8)	0.176
Use of developmental screening tools × Developmental surveillance training	23.23(16)	0.002
Use of standardized developmental assessment tools × Department/unit	30.61(18)	0.001
Use of standardized developmental assessment tools × Developmental surveillance training	10.25(12)	0.594
Referral confidence × Working experience	15.18(8)	0.056
Referral confidence × Developmental surveillance training	19.22(16)	0.027
Referral pathway availability × Working experience	13.01(8)	0.051
Referral pathway availability × Developmental surveillance training	24.78(16)	0.044
Availability of contextual assessment tools × Developmental surveillance training	16.67(12)	0.002
Access to adequate early intervention resources × Profession/area of specialization	6.01(2)	0.175

χ^2: Pearson's Chi-square statistic; df: degrees of freedom. Statistical significance was set at $p < 0.05$.

DISCUSSION

This study examined healthcare providers' practices, facilitators, and perceived challenges in delivering EI services at the CHUK. Overall, the findings reveal a mixed implementation pattern characterized by relatively strong engagement in basic developmental monitoring and teamwork, but significant weaknesses in structured developmental screening systems, referral pathways, workforce capacity, and community outreach.

The findings are consistent with studies conducted in Sub-Saharan Africa, which have reported inadequate developmental screening coverage, workforce shortages, fragmented referral systems, and limited community-based rehabilitation services [13]. A Rwandan study by Tuyisenge et al. demonstrated substantial gaps in developmental delay screening despite increasing recognition of early childhood development needs, with evidence of significant rates of ASQ-detectable developmental delay among infants attending routine health services [6]. Similarly, studies from Ghana have shown that developmental surveillance in routine child health services remains largely dependent on clinical judgment rather than standardized screening tools, resulting in under-identification of developmental delays [14]. Evidence from Ethiopia also indicates that developmental monitoring systems are weak and inconsistently implemented, with limited integration of standardized tools in primary care settings. Across Sub-Saharan Africa, including contexts such as Lesotho, persistent shortages of trained health workers and weak referral systems continue to limit access to timely early intervention services, particularly in rural and underserved communities [7]. The findings demonstrate that while routine developmental monitoring practices are moderately integrated into clinical care, the use of structured early intervention systems remains limited. Nearly half of providers reported always conducting developmental milestone assessments (49.1%), suggesting that informal developmental surveillance is relatively well embedded in routine Paediatric care. Similarly, caregiver education was frequently incorporated into clinical interactions, reflecting alignment with family-centered care principles emphasized in early childhood development frameworks [15]. However, these strengths contrast sharply with major deficiencies in structured screening systems. More than two-thirds of providers reported low confidence in referring children with developmental concerns (64.8%) and lack of clear referral pathways (66.7%). In addition, the use of standardized developmental screening tools was limited, with 42.6% reporting rare or no use. These findings are consistent with evidence from low- and middle-income countries (LMICs), where developmental surveillance is often informal and heavily dependent on clinician judgment rather than standardized tools [16]. The lack of structured screening tools and weak referral confidence suggests systemic fragmentation between detection and intervention services. Without standardized screening and clearly defined referral pathways, early identification becomes inconsistent, delaying access to timely intervention. This has been identified as a major bottleneck in strengthening early childhood development systems globally, particularly in resource-constrained settings [17]. The study identified several important facilitators that support EI service delivery at CHUK. Multidisciplinary teamwork (60.2%) and staff training or mentorship (50.9%) was among the strongest reported facilitators, indicating that collaborative practice and informal capacity-building mechanisms are relatively well established. This is consistent with global recommendations emphasizing multidisciplinary approaches as a core component of effective EI systems [18]. Access to assistive devices was also strongly reported (64.8%), reflecting availability of some essential rehabilitation inputs. These findings suggest that despite systemic gaps, foundational clinical and rehabilitation structures are present and provide an important platform for strengthening EI services. However, these facilitators are undermined by significant infrastructural and system-level weaknesses. More than half of providers reported inadequate rehabilitation spaces and equipment (55.6%), and three-quarters reported a lack of outreach programs (75.9%). Limited caregiver involvement (49.1% disagreement) further highlights weaknesses in family engagement at the service delivery level. These findings are consistent with studies in sub-Saharan Africa showing that EI systems are often facility-centered, under-resourced, and weakly linked to community-based services [19]. The inconsistency in referral pathways further reinforces fragmentation within the system. While some providers acknowledged their existence,

responses were mixed, indicating lack of standardization and poor implementation fidelity.

The study identified several critical system-level challenges affecting EI delivery. Only 39.8% of providers agreed that there are sufficient trained EI specialists, highlighting persistent workforce shortages. This aligns with global evidence showing that limited human resource capacity is one of the most significant barriers to scaling EI services in LMICs [20]. Although half of respondents reported that initial-contact providers routinely screen at-risk children, inconsistencies in referral systems and limited structured surveillance suggest that screening practices are not systematically linked to intervention pathways. This weak continuity between detection and referral has been widely documented in LMIC health systems. Notably, caregiver-related challenges were also highlighted. More than half of providers reported that caregivers are not adequately informed about early developmental signs (51.0%). However, cultural beliefs and stigma were not widely perceived as major barriers, with over half of respondents disagreeing that these factors significantly influence care-seeking behaviours [21]. This suggests that the primary barrier may be lack of awareness rather than resistance due to cultural norms. This finding is important because it shifts the focus from cultural explanations of delay to health system-driven gaps in early identification and caregiver education.

The analysis found no statistically significant associations between provider socio-demographic characteristics and EI practices or perceived challenges. Gender, age, marital status, profession, and years of experience were not significantly associated with screening practices, referral confidence, or perceived system barriers. This suggests that implementation challenges are primarily driven by systemic and structural factors rather than individual provider characteristics. Similar findings have been reported in other LMIC settings, where organizational constraints such as lack of tools, weak systems integration, and insufficient training environments play a more dominant role than individual demographics [22]. However, the finding that more experienced providers demonstrated slightly higher referral confidence suggests that experiential learning may partially mitigate training gaps. This highlights the importance of structured mentorship and continuous professional development in strengthening early intervention systems.

The study was conducted at a single tertiary referral hospital, which may limit generalizability to district hospitals, health centers, and community-based settings. The findings relied on self-reported practices and perceptions, making them susceptible to recall bias and social desirability bias.

Some professional cadres were represented by relatively small sample sizes, reducing statistical power for subgroup analyses.

The study focused exclusively on healthcare providers and did not include perspectives from caregivers, children with developmental delays, community health workers, or policymakers.

The findings have important implications for child development and rehabilitation policy in Rwanda. The limited use of standardized developmental screening tools and absence of clear referral pathways suggest a need for national guidelines that integrate developmental surveillance into routine pediatric and primary healthcare services.. Strengthening pre-service and in-service training on developmental screening, referral systems, and family-centered care could improve early identification of developmental delays. Furthermore, expanding community-based rehabilitation programs and integrating early intervention services within district hospitals and primary healthcare facilities may improve service accessibility and reduce the burden on tertiary referral hospitals.

The findings support current national efforts aimed at strengthening early childhood development and inclusive rehabilitation services through multidisciplinary and decentralized models of care.

CONCLUSION

This study demonstrates that while healthcare providers at CHUK routinely engage in developmental monitoring and caregiver education, significant gaps remain in the implementation of comprehensive early intervention services for children with developmental delays. Limited use of standardized screening tools, unclear referral pathways, inadequate rehabilitation infrastructure, insufficient specialized personnel, and weak community outreach mechanisms continue to hinder effective service delivery. Multidisciplinary

collaboration, access to assistive devices, and staff mentorship emerged as important facilitators. Strengthening provider capacity, institutionalizing developmental screening, establishing clear referral systems and expanding family- and community-centered services are critical to improving early identification, timely intervention, and developmental outcomes for children in Rwanda. Future mixed-methods and multicenter studies incorporating multiple stakeholder perspectives are recommended.

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Review Article

Open Access

Sociocultural Perspectives on Palliative Care Across East African Community Countries: A Narrative Review with Thematic Synthesis

Diane Andrea Ndoli[1], Raissa Mucyo[1], Jason Bakundukize[1], Vedaste Hategekimana[1], Christian Ntizimira[1,*]

[1]*The African Center for Research on End-of-Life Care (ACREOL Global), Kigali, Rwanda*

ABSTRACT

INTRODUCTION: East African Community (EAC) partner states face a dual burden of HIV/AIDS and rapidly rising non-communicable diseases (NCDs), yet access to palliative care, including basic pain relief, remains limited, and sociocultural dynamics strongly shape how such care is understood and accepted. This review synthesized the sociocultural, spiritual, and clinical palliative care needs of patients with advanced NCDs across the eight EAC partner states, and to examine how their structural support needs differ from those of people living with HIV/AIDS.

METHODS: A structured narrative synthesis was conducted. PubMed, Scopus, and Web of Science were searched using terms combining geographic and palliative care concepts; records were screened against Population–Concept–Context criteria, and 21 core publications were thematically synthesized, with detailed data extraction performed on ten primary empirical studies.

RESULTS: Three themes emerged: (1) severe, region-wide deficits in pain and symptom management compounded by restrictive opioid regulation; (2) pervasive communication taboos and prognostic silence that obstruct disclosure and future planning; and (3) the centrality of spirituality, religious networks, and indigenous belief systems, which providers are often unprepared to engage. NCD cohorts reported acute informational deficits, whereas HIV/AIDS cohorts historically reported predominantly structural and financial needs.

CONCLUSION: Culturally grounded communication strategies, spiritual-care competence, and equitable opioid access are regional priorities; localized primary research is urgently needed in Burundi, Somalia, South Sudan, and the Democratic Republic of the Congo.

***Corresponding author:**
Dr. Christian Ntizimira

African Center for Research on End-of-Life Care (ACREOL Global), Kigali, Rwanda

Email: christian.ntizimira@acreol.org

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INTRODUCTION

East African countries face a challenging and evolving health issue shaped by a dual disease burden: persistent communicable diseases, particularly HIV/AIDS, alongside a rapidly rising prevalence of non-communicable diseases (NCDs) such as cancer, cardiac disease, neurological disease, and more [1,2]. This growing burden places immense pressure on already constrained health systems, while rising mortality and prolonged suffering highlight the urgent need for accessible and comprehensive palliative care services [3]. Palliative care, defined by the World Health Organization as a holistic approach addressing physical, psychological,

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social, and spiritual dimensions of suffering [1], offers a critical response to these challenges. Yet despite its recognized benefits, access to essential palliative care including basic pain relief remains limited across much of the region, contributing to substantial unmet needs among patients and families [1].

The development of palliative care across East Africa Community countries has been uneven. Uganda and Kenya stand out for their comparatively advanced palliative care systems, largely due to early and sustained engagement from non-governmental organizations responding to the HIV/AIDS epidemic [1,4,5]. These efforts helped strengthen government involvement and expand service provision over time. In contrast, many African countries continue to show minimal or no palliative care development [4,6]. As patterns of illness shift, models originally designed to meet the acute needs of HIV/AIDS patients now face pressure to adapt to the growing, diverse demands of individuals with NCDs, a transition often hindered by limited public health resources and inconsistent system-wide commitment [1].

Sociocultural dynamics play a central role in shaping how palliative care is understood, accepted, and delivered throughout the region. Spirituality, traditional belief systems, communication norms, and family structures profoundly influence patients' experiences of illness and their expectations of care. For instance, the region reflects a diverse continuum of care models, ranging from family-driven and community-supported frameworks in the Democratic Republic of Congo (DRC) to deeply complex cultural attitudes toward pain expression, fatalism, and stoicism seen in Somali communities [7,8]. Furthermore, efforts to culturally ground end-of-life care are exemplified by the integration of the Ubuntu philosophy emphasizing shared humanity and interconnectedness into structural care delivery [9]. However, when these local ways of finding meaning collide with formalized healthcare systems, mismatches occur; healthcare providers frequently express discomfort or marginalize indigenous spiritual practices (such as ancestral beliefs or witchcraft) in favor of major global religions [10].

While structural integration and rapid policy development have advanced in certain nations, severe gaps remain regarding implementation capacity, clinician preparedness, and equitable resource allocation [2,11]. Crucially, historical end-of-life research in sub-Saharan Africa has predominantly focused on HIV/AIDS [12]. To address the changing epidemiological landscape, this narrative synthesis examined sociocultural perspectives on palliative care across East African Community (EAC) countries, with particular attention to Kenya, Uganda, Rwanda, Burundi, the Democratic Republic of the Congo (DRC), South Sudan, Somalia, and Tanzania. The inclusion of these nations reflects the expanding geopolitical footprint and historical health-system cross-linkages of the EAC.

METHODS

Design

This paper utilizes a structured narrative synthesis methodology to collate, analyze, and map the literature surrounding palliative care delivery across eight target East African Community nations. Given the highly qualitative, heterogeneous, and deeply contextual nature of sociocultural data, a narrative synthesis framework was selected over a rigid scoping review protocol to allow for a comprehensive thematic integration of both empirical studies and foundational regional perspective pieces.

Search Question

The core question directing this synthesis is: *What are the specific sociocultural, spiritual, and clinical palliative care needs, particularly regarding pain management and communication taboos of patients with advanced non-communicable diseases (NCDs) such as cancer, and how do their structural support needs differ from those of patients living with HIV/AIDS in the East African Community region?*

Data Sources and Search Strategy

Literature was identified using a targeted search strategy across multi-disciplinary databases (PubMed, Scopus, and Web of Science). Search strings combined terms relating to the geographic setting ("East Africa", "Rwanda", "Kenya", "Tanzania", etc.) with core concept blocks ("palliative care", "terminal care", "hospice", "cultural beliefs", "spirituality", "pain") (Table 1). Searches were completed in April 2026; of the 295 records retrieved across the three databases (Table

Table 1: *Database Search Strategy and Records Retrieved by Source*

Database	Search Terms	Records Retrieved (n)
PubMed	palliative care, hospice care, end-of-life care, pain management, culture, spirituality, sociocultural, taboo, cultural beliefs, attitude to death, East Africa, Rwanda, Kenya, Uganda, Tanzania, Burundi, South Sudan, Somalia, Democratic Republic of Congo	94
Scopus	palliative care, hospice care, end-of-life care, pain management, culture, spirituality, sociocultural, taboo, cultural beliefs, attitude to death, East Africa, Rwanda, Kenya, Uganda, Tanzania, Burundi, South Sudan, Somalia, Democratic Republic of Congo	118
Web of Science	palliative care, hospice care, end-of-life care, pain management, culture, spirituality, sociocultural, taboo, cultural beliefs, attitude to death, East Africa, Rwanda, Kenya, Uganda, Tanzania, Burundi, South Sudan, Somalia, Democratic Republic of Congo	83

1), duplicates and ineligible records were removed through title, abstract, and full-text screening.

Eligibility and Study Selection

Literature was evaluated using a modified PCC (Population–Concept–Context) framework: Population (Palliative care patients, family caregivers, or healthcare professionals; Concept (Sociocultural barriers, spiritual support, communication norms, or symptom management experiences; and Context (East African Community partner states). After applying eligible criteria, 10 eligible full-text stuidies were included in the synthesis.

Synthesis Approach

Using the narrative synthesis, we thematically maped insights across papers to capture the sociocultural realities of the region from 10 primary empirical studies representing the core thematic pillars of communication, spirituality, and resource shortages were subjected to detailed data extraction (Table 2). Methodological quality appraisal was not formally conducted due to the inclusion of diverse essay, perspective, and qualitative formats, which limits comparative scoring but maximizes thematic breadth.

RESULTS

Study Characteristics and Reported Sociocultural Dimensions of Palliative Care

Table 2 profiles ten empirical studies published between 2006 and 2022, spanning six settings: Kenya, Uganda, Tanzania, Rwanda, the DRC, and Somali populations (via a diaspora study), plus one multi-country regional evaluation. Designs are predominantly qualitative or descriptive — ethnography, interviews, focus groups, and field studies, alongside cross-sectional and clinician surveys and one mixed-methods study; the largest sample was 420 Rwandan clinicians. Populations covered advanced cancer patients, people living with HIV/AIDS, healthcare professionals, family caregivers, religious leaders, and policy actors.
Collectively, the studies document severe unmet pain and information needs, heavy financial and nutritional strain on families, entrenched taboos against discussing death, provider discomfort with indigenous spiritual practices, misconceptions among religious leaders, cultural expectations of stoicism, and persistent gaps between rapid policy expansion and actual service delivery, with community-based oral morphine programs and nurse-led task-sharing emerging as the most promising responses.

Cross-National Symptom Management and Clinical Deficits

Across all EAC nations, the management of physical symptoms, most notably severe pain, presents a uniform clinical crisis compounded by structural limitations [1]. Pain is consistently validated as the most distressing problem for advanced cancer patients in Kenya and Uganda [13] and matches the 43% unmet pain relief need reported by HIV-positive cohorts in Rwanda [11].
While community-based oral morphine initiatives have shown remarkable localized success in transforming rural care across Kenya and Uganda, systemic barriers such as restrictive opioid legislation and interrupted supply chains remain a persistent barrier throughout the broader continent [4,16]. Although Grant et al. [16] also report

Table 2: *Characteristics and Key Sociocultural Findings of the Ten Primary Empirical Studies Included in the Synthesis*

#	Study Details	Country Focus	Study Design & Setting	Population / Disease Focus	Key Sociocultural & Palliative Care Findings
1	Harding et al. (2014) [13]	Kenya, Uganda	Multi-center, self-report clinical survey	Advanced Cancer patients	Pain is identified as the most severe physical problem. Severe information deficits exist; lack of information for future planning is a critical unmet need. Higher spiritual well-being correlates with older age.
2	Uwimana & Struthers (2007) [11]	Rwanda	Descriptive cross-sectional survey	People Living with HIV/AIDS (PLWHA)	High unmet structural and clinical needs: 77% required financial assistance, 44% required nutritional support, and 43% reported lacking effective pain relief.
3	Lewis et al. (2017) [14]	Tanzania	Qualitative interview study in hospital settings	Healthcare professionals (HCPs) and general inpatients	Revealed a profound cultural taboo against discussing death or terminal prognosis ("We never speak about death"). Hospitals are culturally viewed as superior environments for acute symptom control.
4	Kale (2011) [10]	Uganda	Qualitative ethnographic study at Hospice Africa Uganda	Palliative care workers and spiritual counselors	Providers are comfortable addressing mainstream global religions but experience high discomfort with indigenous spiritual expressions (e.g., witchcraft/cursing), leading to patient marginalization.
5	Rialem et al. (2020) [15]	Kenya	Mixed-methods: Survey and Focus Group Discussions	Community-based religious leaders	Religious leaders are vital partners for talking about dying, but severe misconceptions persist, such as the belief that palliative care actively hastens death.
6	Grant et al. (2011) [16]	Uganda, Kenya, Malawi	Rapid evaluation field studies in rural settings	Rural healthcare providers and palliative care patients	Confirms that community-based deployment of oral morphine serves as a vital intervention that significantly benefits patients and empowers rural staff.
7	Luyirika et al. (2022) [2]	Regional (Multi-country update)	Multi-country policy and health system progress evaluation	National health infrastructure, ministries, and policy leaders	Documents rapid policy expansion and integration of palliative care into Universal Health Coverage frameworks, while noting major persistent gaps in local service delivery.
8	Lofandjola et al. (2017) [17]	Democratic Republic of Congo (DRC)	Qualitative descriptive field study in Kinshasa	Families and extended kinship networks caring for advanced illness	Captures how resource deficits turn care into an informal system; care is driven heavily by family and religious communities to compensate for systemic healthcare gaps.
9	Finnström et al. (2006) [7]	Somalia (diaspora study, Sweden)	Qualitative conceptual exploration	Somali community perspectives on pain	Documents a pervasive cultural expectation of stoicism regarding pain expression, which extends down to children (ages 6–8) who are expected to mask physical suffering.
10	Moreland et al. (2021) [3]	Rwanda	Quantitative clinician survey across health facilities	420 medical clinicians (physicians and nurses)	Assessed educational gaps; indicates nurses score higher than physicians in communication, ethical knowledge, and family-centered care, showing strong potential for task-sharing models.

findings from Malawi, only the Uganda and Kenya components of that evaluation were drawn on here, consistent with the EAC-bounded scope of this review.

The findings across studies indication that the primary divergence between patient populations relates to structural vs. acute clinical resource strains.

Socioeconomic and Structural Exhaustion

Patients navigating long-term illness face severe, compounding structural deficits. For instance, data from Rwandan cohorts demonstrates that financial strain (77%) and nutritional insecurity (44%) often eclipse standard medical care needs, demonstrating how chronic illness drains family resources over time [11]. These HIV/AIDS cohort data, however, predate the large-scale expansion of antiretroviral therapy in Rwanda and should be read as a historical benchmark rather than a contemporary comparison. This matches patterns in the DRC, where scarce painkiller access turns palliative care into an informal, economically draining family survival model [8,17].

Clinical Communication Gaps

Advanced NCD cohorts (such as cancer patients) display a higher vulnerability to severe information deficits regarding their disease trajectory and future planning, frequently driven by institutional and familial communication failures [13].

Communication Taboos and Prognostic Silence

A dominant sociocultural barrier across the region is the pervasive cultural taboo surrounding explicit discussions of death, dying, and terminal prognoses [14,18]. In qualitative investigations within Tanzania, healthcare providers explicitly noted an institutionalized silence, summarizing the cultural norm as: "We never speak about death" [14]. This silence directly triggers severe clinical consequences; patients facing terminal NCDs in Kenya and Uganda identify the lack of clear prognostic information as one of their most damaging unmet needs, directly preventing them from executing essential future planning [13].

This protective silence is further complicated in settings like Somalia. While direct clinical palliative care studies within the country are absent, proxy sociocultural data collected among Somali diaspora women living in Sweden demonstrates a rigid cultural expectation of stoicism regarding physical suffering [7]. This strict expectation of pain control and endurance extends even down to children between the ages of 6 and 8, which heavily impacts symptom communication and underscores the necessity for healthcare providers to develop deep cultural competence during clinical end-of-life mapping [7].

Spirituality, Religious Networks, and Indigenous Belief Systems

Across the synthesized literature, spirituality emerged as a central organizing framework through which patients and families interpret serious illness, suffering, and death. In Kenya and Uganda, higher spiritual well-being among advanced cancer patients was associated with older age, suggesting that spiritual resources operate as culturally embedded coping assets that accumulate across the life course [13]. In the DRC, religious communities function as a de facto arm of the care system itself, providing material, emotional, and spiritual support that compensates for profound gaps in formal service delivery [17].

The evidence nevertheless reveals a marked asymmetry in provider preparedness. Ethnographic work at Hospice Africa Uganda found that palliative care workers were comfortable engaging patients' mainstream global religious traditions but expressed substantial discomfort when confronted with indigenous spiritual expressions such as ancestral beliefs, cursing, or witchcraft — a discomfort that can result in the marginalization of patients whose meaning-making draws on these frameworks [10]. This tension is consequential in a region where biomedical systems and local cosmologies coexist, and where culturally grounded models such as the Ubuntu philosophy of shared humanity have been proposed as bridges between the two [9].

Religious leaders themselves represent both a critical asset and a potential barrier. In Kenya, community-based religious leaders were identified as vital partners in initiating conversations about dying, yet serious misconceptions persisted among them, including the belief that palliative care actively hastens death [15]. Taken together, these findings indicate that spiritual-care competence — including structured engagement with indigenous belief systems and deliberate partnership with faith leaders — is as fundamental to palliative care delivery in the region as clinical symptom control.

DISCUSSION

This review indicates that the sociocultural architecture of palliative care in the EAC region rests on three interlocking realities: unrelieved physical suffering, culturally patterned silence around death, and spiritually mediated meaning-making.

The convergence of these themes across otherwise heterogeneous national contexts suggests that clinical models imported without cultural adaptation are unlikely to succeed. The documented communication taboos [13,14] do not merely delay disclosure; they actively prevent patients from executing future planning, settling family and financial affairs, and accessing goal-concordant care. Approaches to truth-telling therefore need to be renegotiated within, rather than against, local norms — for example through gradual, family-mediated disclosure and through the involvement of trusted religious leaders [15].

The findings also carry direct workforce and policy implications. Evidence from Rwanda that nurses outperform physicians in communication, ethics, and family-centered care domains [3] supports task-sharing models in which nurses anchor community-level palliative care, an approach consistent with the demonstrated success of community-based oral morphine programs in rural Uganda and Kenya [16].

At the policy level, the rapid integration of palliative care into Universal Health Coverage frameworks [2] has not yet been matched by local service-delivery capacity, echoing the region's wider implementation gap [4]. Finally, the divergence identified between the historically documented structural needs of HIV/AIDS cohorts [11] and the informational needs of NCD cohorts [13] should be interpreted cautiously, given that the available HIV evidence predates modern antiretroviral scale-up; contemporary comparative studies are needed.

This review showed some literature gaps to consider. The first is the constrained and highly uneven distribution of the available empirical literature across the eight studied nations, which prevents drawing sweeping, uniform conclusions for the entire East African Community region. While countries like Uganda and Kenya benefit from a relatively robust corpus of documented palliative care frameworks and empirical assessments [1,5], the evidence base for a significant portion of the bloc remains severely limited or indirect.

The structural and geographical gaps in the regional evidence base are characterized by the following specific limitations: Complete absence of local primary evidence in Burundi, where direct, localized primary literature on the sociocultural or clinical dimensions of palliative care is entirely absent. Consequently, assertions regarding patient-provider dynamics or healthcare system integration in Burundi must rely on broader, translated sub-Saharan regional models, rather than verified domestic data.

There is a lack of Direct Palliative Care Research in Somalia: The available literature for Somalia does not capture direct palliative care or hospice delivery systems. Instead, the evidence base is restricted to proxy sociological explorations of cultural attitudes toward pain expression, fatalism, and general healthcare interactions within Somali communities, largely conducted among diaspora populations outside Somalia [7,19]. While these insights are vital for building cultural competence, they lack direct clinical application to end-of-life care pathways.

Although formal palliative care guidance has been articulated for South Sudan [20], there is a profound scarcity of active field research detailing how these guidelines translate to patient experiences. The expected barriers are inferred primarily from broader maternal and antenatal health utilization studies rather than dedicated end-of-life evaluations [21].

Despite its massive geographical and population footprint within the expanded EAC, the DRC remains deeply underrepresented in global palliative care literature. Extant data is heavily localized to qualitative snapshots within urban centers like Kinshasa, capturing informal family survival models but failing to reflect the diverse rural realities of the wider nation [8,17].

Acknowledging these extensive empirical limitations is essential. They highlight that the findings presented in this synthesis represent a fragmented regional landscape rather than a single, uniform East African reality. Rather than undercutting the value of this review, these profound gaps underscore an urgent, explicit mandate for localized, country-specific primary research and clinical intervention studies across these underrepresented nations.

CONCLUSION

Palliative care needs across the EAC partner states are shaped as much by sociocultural and spiritual dynamics as by clinical resource constraints. Pain relief remains the most urgent and universal unmet clinical need, but its resolution is inseparable from communication norms that silence prognostic discussion and from spiritual frameworks that providers are frequently unprepared to engage. Strengthening regional palliative care will require culturally negotiated communication strategies, structured spiritual-care training that includes indigenous belief systems, nurse-led task-sharing, and sustained investment in opioid access. Above all, the profound evidence gaps in Burundi, Somalia, South Sudan, and the DRC constitute an explicit mandate for localized, country-specific primary research.

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Rwanda
Public Health Bulletin

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The Rwanda Public Health Bulletin (RPHB) is a printed and open access, peer-reviewed journal, published as the flagship scientific and technical periodical publication. RPHB is a public health bulletin launched in March 2019 by the Rwandan Ministry of Health, through the Rwanda Biomedical Centre (RBC) in collaboration with the CDC Foundation and with support from Bloomberg Philanthropies Data for Health Initiative.

Mission

To serve as a scientific information dissemination platform of national and international significance, mainly in areas related to the Rwanda Ministry of Health's essential mission to strengthen national and local health systems and improve the health of the people of Rwanda. The Rwanda Public Health Bulletin publishes disease surveillance summaries, public health response guidelines, public health notices, case reports, outbreak reports, original research papers, and policy briefs among others. It generally features issues of importance to its targeted audience, which is health professionals, academic researchers, policymakers and anybody interested in health issues. Articles for publication are received from doctors, nurses, allied health professionals, students, policymakers, government bodies, non-governmental bodies and others.

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INSTRUCTIONS TO AUTHORS

All works submitted to this bulletin will have to belong to the types of articles stated below:

1. ORIGINAL RESEARCH

Referred to as "Primary Research" pioneer in a determined domain. It can be from various aspects: Clinical features, pathophysiology, biochemistry, molecular biology, etc.

THE TITLE

The title of the article should be concise and informative. It should contain enough thoughts on the subject.

ABSTRACT

Abstract of 250 words maximum must accompany each manuscript and be divided into 4 paragraphs with the following headings and MeSH keywords:

Introduction: stating the purposes/aims of the work; the research undertaken, the hypothesis tested or the procedure evaluated.
Materials and methods: briefly stating what was done and what materials were used, including the number of subjects, the methods to assess the data and to control bias.
Results: Providing key findings of the study, including indicators of statistical significance, actual numbers, as well as percentages.
Conclusion: Summarizing in 1 or 2 sentences the work on the basis of the findings. It emphasizes new and important aspects of the study or observations.

THE MAIN TEXT

The text of observational and experimental articles is divided into sections with the following headings: Introduction: should always begin the text, and requires brevity and focuses. It conveys the nature and purpose of the work, and quotes the relevant literature. Only strictly pertinent background information is necessary for understanding why the topic is important. We suggest the final paragraph clearly states the hypothesis or purpose of the study.

METHODS

Details of clinical and technical procedures should follow the introduction. A clear description of the selection of the observational or experimental subjects should be given. The identification of all aspects of the study, its reasoning, and the related relevance should be explicitly justified. In case, the study was done in a particular way, the guiding principles should all be clarified. Exclusion and inclusion criteria or partial inclusion, the reliability index, the confidentiality index, the analysis step, and the data collection processes should be also carefully specified. This section should provide sufficient details on the methods, instrumentation, procedures, all drugs and chemicals used (including generic names, doses, routes of administration). It should allow other workers to reproduce the study if necessary.
This section should also state the self-evaluation of the study by: independent/consensus readings blinded or unblinded to other information and estimate the fluctuation of recall biases by random ordering of studies.

Be clear about the retrospective or prospective nature of the study. Finally, provide references to established methods, including statistical methods that have been published, forthcoming, or that may not be well known. New description or substantially modified methods may be used however, give reasons for the use of these techniques, and evaluate their limitations. Statistical methods should be described with enough details to enable a knowledgeable reader with access to the original data to verify the reported results. A general description of methods would be defined in the methods section, whereas a specific statistical method used into analysis would be summarized in the results section. Any general use of the computer program should be

specified, and more details have to be clarified about any randomization issues.

RESULTS

Logical sequence of presentation of results is required in the text; along with tables, and illustrations. Repetition of data from illustrations into the text should be avoided; however, emphasize or summary of only important observations would be helpful. Avoid the ‘’non-technical use’’ of technical terms in statistics which should be defined and reserved for the right purpose. Moreover, define all those statistical terms aside with or including abbreviations and/or most used symbols. Any complication and/or unexpected finding should be reported and the more possibly explained and the author should report lost to follow up and dropouts from a clinical trial.

DISCUSSION

Use ample subheadings. Emphasize the new and important aspects of the study and the conclusions that follow from them. Avoid repetition of details included in other parts. This section requires the mention of the implication of the findings, and their limitations for future research, involving relating the observations to other relevant studies.

Finally, the conclusions should be linked to the goals of the study; though mostly avoiding:

Unqualified statement not completely supported by the data

Statement on economic benefits and costs unless the report includes economic data and analyses

Claim of priority and alluding to work that has not been completed.

Whereas new hypotheses could be suggested when warranted, but they should be clearly labeled as such and recommendations, when appropriate and needed, may be given.

Acknowledgments

List all contributors who do not meet the criteria of authorship, such as those who provided purely technical help, writing assistance, or a department chair who provided only general support; and their respective contribution will be headed as provided. Everybody must have given written permission to be acknowledged. References: References should be numbered consecutively in the order in which they were first mentioned in the text. They will be identified in the text, tables, and legends by arabic numbers. This bulletin uses the IEEE style (Institute of Electrical and Electronics Engineers) for referencing the citations. It is advised to avoid citations or personal communication unless they provide essential and pertinent information. In all case, the name of the person and date of communication should be cited in parentheses in the text.

2. CHECKLIST FOR SURVEILLANCE REPORTS

Disease surveillance summaries are reported following the checklist below:
Title: Compose a title that includes the name of the health condition, population, time and place.
Abstract: Provide a structured abstract including the following sub- headings: Background; Objectives; Methods; Results; and Conclusion.

INTRODUCTION

Context: Summarize the current situation regarding the health condition under surveillance and identify why it is important. Objectives: State the objective of the surveillance report.

METHODS

Setting: Describe the setting, locations and dates of the surveillance period.
Population: Describe the population under surveillance. Definitions: Provide definitions for each health event under surveillance, including

case definitions and any public health interventions. **Information sources**: Describe all data sources, including the objective of any surveillance systems, what data were collected and how data were gathered, transferred and stored. Supplementary data: If appropriate, note where to access supplemental material (e.g., www.opendata.gc.ca). **Data quality, missing data and reporting delays:** Describe how the data quality was assessed. Explain how missing data were addressed. If data is reported by date of diagnosis or symptom onset, include a statement about whether the data for the most recent periods may be revised.

DATA ANALYSIS

Describe any analytical methods used providing sufficient detail to enable a knowledgeable reader with access to the original data to judge its appropriateness and to assess the reported results.

RESULTS

Descriptive: Provide a summary of the descriptive data, including demographics.
Data Quality: Report on data quality (e.g., completeness, missing data, under reporting)
Analytic data: Provide a summary of the analysis including (when indicated) estimates of trends. When applicable, point estimates should include appropriate indicators of measurement error such as 95% confidence intervals (e.g., average annual percentage change used to describe trends or odds ratios used to describe subgroup differences).
Figures: Create the minimum number of figures to highlight key results. Create a title that includes person, time and place.

DISCUSSION

Key results: Summarize key results with reference to study objectives
Comparison: Consider these findings in relation to the current literature. Strengths and weaknesses: Discuss the strengths and weaknesses of the study (data quality, completeness, sources of potential bias). Interpretation and generalizability: Provide a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies and other relevant evidence.
Conclusion: Ensure conclusions address objectives and follow from the results.

3. PUBLIC HEALTH NOTICES / OUTBREAK REPORTS

Following the Center for Disease Control recommendations, for public heath notices and outbreak reports to be published they need to cover all four components as stated below:

INTRODUCTION

Generally, the introductory paragraph should begin with 1 to 3 sentences establishing the existence of the outbreak or underlying public health problem. E.g., "On January 2, 2008, the Nevada State Health Division contacted CDC concerning surveillance reports received regarding two persons recently diagnosed with acute hepatitis C." The introductory paragraph also usually contains: a) a statement that an investigation was conducted, when and by whom; b) the most important finding(s); c) the actions taken to stem the outbreak; and d) a statement of the public health implications and actions that should be taken in response to the investigation. Investigation and results: First, present the initial investigation and its findings. This might include: 1) a description of the setting and a statement of how the outbreak came to the attention of health authorities; 2) a clinical description of the index case or initial cases; 3) initial key test results; and 4) hypothesis generation activities and results. Next, summarize the full investigation, including: case definition, case-finding activities, method of investigation, and results. Cases should be counted and described by clinical characteristics, treatment, and outcome, as well as time, place, and person descriptive results. Next, present the methods and results of any analytic epidemiologic studies (e.g.,

cohort or case-control studies). Finally, provide the results of any relevant microbiologic, genetic, or toxicologic results, followed by the results of any testing of environmental samples. Public health response: When appropriate, a brief description summarizing any public health interventions taken and the results of the interventions follows.

DISCUSSION

Same as for a Full Report, except that a Limitations paragraph might not be required for an Outbreak Report.

4. POLICY BRIEFS

This bulletin will use guidelines on reporting/ publishing policy notes as they are suggested by the Center for Disease Control (CDC). As the CDC defines them; Policy Notes are intended to announce new official policies or recommendations (e.g., from ACIP or CDC). These reports can be thought of as briefs. Maximum word count at submission is 1,400 words. Up to three tables, figures, or boxes may be included. Policy Notes contain no Discussion or Limitations, and a summary box is not required. Although policy notes or brief might vary, following is a rough guide of what basic notes should have: Introduction: The introductory paragraph should be limited to 150–200 words. It might contain all or some of the following components: a brief introductory statement orienting the reader to the topic and placing it in context, a brief description of the public health problem, a brief statement of the rationale for the policy or recommendation, mention of the most important parts of the policy or recommendations, and one or two sentences stating the conclusions and the public health implications of the new policy or recommendations.

BACKGROUND

The Policy Note should include a paragraph after the introduction that summarizes background information relevant to the policy or recommendation that can help the reader understand the context and need for the policy or recommendation.

Methods: Should include a summary of the methods used to establish the policy or recommendation, including answers to some or all of these questions: Who was involved in the production of the guidelines or recommendations, and how? What evidence base was considered? What was the rationale for considering this evidence base? Was other evidence excluded from consideration and, if so, why? Rationale and evidence: The Policy Note should provide a concise review of the rationale for the policy or recommendation and a descriptive review of the scientific evidence used to establish it. It should include an explanation of how the policy or recommendation adds to, or differs from, relevant policies or recommendations established previously. Presentation of the policy or recommendation: The policy or recommendation should state clearly when it takes effect and to whom and under what circumstances it applies.

DISCUSSION OR COMMENT

The Policy Note should comment on the likely impact of the new policy or recommendation and plans for assessment of the policy or recommendation

5. CASE REPORTS

These are reports of an individual patient on their symptoms, treatment reactions on a disease or condition of interest. These reports normally focus on unusual reactions or occurrences. Similar cases to other research reports, case reports might include a literature review of previous similar. Case reports might also address positive patient outcome on particular treatment guidelines or individual impact of a particular intervention. These are mainly used for educational and decision-making purposes. Case reports are normally reported following a checklist found at the CARE Guidelines.

6. CASE STUDIES

We recommend authors to follow the "EQUATOR Network" for ample explanations and guidelines in the writing of such articles. They have to be well-described case studies on health care interventions of public health concern. These could be:

Rigorous assessments of processes and program interventions.

Recommendations on possible health interventions.

Never on individual patient (= case report)

7. COMMENTARIES / OPINION / METHODOLOGY ARTICLES

We recommend authors to follow the "EQUATOR Network" for ample explanations and guidelines in the writing of such articles. Though these articles are moderated, they should be:

Short, focused, opinionated to previous articles or any subject related to the journal entirely.
Contemporary and focusing on specific issues.
Normally up to 800 words.

Frank critics to the journal are bravely motivated and would be as much as possible published.

8. FORMATTING THE MANUSCRIPT

Please note that articles which are not correctly formatted will be returned to the authors

Format text: Style: No Spacing, Single column, Single Spacing
Font: Single Spacing, Times New Roman - size 12
Titles: Capitals and bold, size 14
Format tables: Times New Roman, Font size 9
No vertical lines. Horizontal lines in the table can be removed. No table should be larger than a single A4 page. Footnote should be size 9 and italic

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