

# Experience and Perception of Patients and Healthcare Professionals on Acute Leukemia in Rwanda: A Qualitative Study

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**Purpose:** To explore challenges associated with the timely diagnosis, therapy, and prognosis of acute leukemia in Rwanda.

**Methods:** This is a qualitative study using a phenomenological approach that involved patients, patients' guardians, and healthcare professionals such as physicians from district hospitals and specialists from referral hospitals, as well as healthcare administrators. The primary data were collected from district and referral hospitals and central healthcare administration in Rwanda. The data were collected between July and October 2019. In-depth interviews were conducted, and thematic analysis was employed to interpret the results.

**Results:** We identified barriers to seeking healthcare such as (i) insufficient knowledge within the population may lead patients and their guardians to consult traditional healers before seeking qualified medical care, and (ii) financial constraints that preclude payment of healthcare fees or other out-of-pocket cost related to diagnosis and treatment. We also observed that the referral system is tedious and primary healthcare facilities lack the competence and resources for the necessary diagnostic practices. Both may further delay diagnosis and therapy. Accordingly, healthcare professionals at the referral hospitals stated that most patients were seen at an advanced stage of the disease. For the treatment of acute lymphoblastic leukemia (ALL), only chemotherapy is utilized in Rwanda, while bone marrow (BM) transplantation is not available. Palliation is the only available treatment for the vast majority of Rwandan acute myeloid leukemia (AML) patients.

**Conclusion:** ALL and AML are likely under-reported in Rwanda and diagnosis may be delayed, which may be explained by patient-related factors (lack of knowledge, financial constraints), a tedious referral system, and suboptimal diagnostic resources.

**Keywords:** leukemia, lymphoblastic, myeloid, acute, healthcare delivery, Rwanda

## Introduction

Acute myeloid leukemia (AML) and acute lymphoblastic leukemia (ALL) are hematological malignancies characterized by clonal expansion of myeloid (AML) or lymphoid (ALL) blasts in the bone marrow, blood, or other tissues. Single-country studies have documented that, among AML patients, those of African descent are younger at the time of diagnosis, and have a poorer prognosis, than those of Caucasian origin.<sup>1</sup>

Epidemiological information on acute leukemia (ALL and AML) in Sub-Saharan Africa is scarce and usually based on extrapolated data from other regions.<sup>2-5</sup> Moreover, the reported incidence of acute leukemia (and other cancers) is lower in developing countries than in the Western world; this difference persists also using age-adjusted estimates of incidence.<sup>6,7</sup> This low reporting rate may be attributed to the reduced availability and utilization of diagnostic services in developing countries.

Several studies investigated the role of socio-economic factors on the healthcare-seeking behavior of the population, but the conclusions drawn vary considerably. For example, some studies have identified poverty and low

education as barriers to seeking healthcare.<sup>8</sup> Other authors proposed that community engagement in healthcare programs as well as the quality of these services might be the most important determinants.<sup>9–12</sup> In some World regions, rural population, women, as well as children with many siblings were reported to have very limited access to healthcare services.<sup>13–16</sup>

The assessment of health services has usually focused on availability as well as geographic and financial accessibility. The willingness of patients to visit health services is usually overlooked. Yet the user's attitudes (perceptions) and expectations as well as the quality of healthcare services (infrastructures and healthcare professionals) are important determinants of the utilization of healthcare services.<sup>17</sup> Thus, patients often do not visit referral hospitals, even when encouraged to do so, until the disease has increased in severity.<sup>10,18,19</sup>

A recent epidemiological survey on demographics and outcome of acute leukemia in Rwanda showed low apparent incidence rates, early onset (affecting younger patients), and poor prognosis compared with developed countries.<sup>7</sup> In addition, Rwanda recently stated that only about 3000 new cancer cases are registered each year, while the World Health Organization (WHO) estimates that these cases are approximately 10,000 each year.<sup>20</sup> We speculated that the low incidence rates of acute leukemia observed in Rwanda may have been amplified by a low detection rate due to either poor healthcare-seeking behavior and/or limited diagnostic capacities. Over the past decade, a high rate of the Rwandan population had healthcare coverage through health insurance schemes, especially the community-based health insurance (CBHI), and the number of health facilities at different geographic locations has increased. Moreover, Rwanda has developed community-based and participatory strategies for problem solving, a program commonly known as “Ubudehe” in Kinyarwanda. Launched in 2002, its current version was conceived in 2015 and consists of 4 socio-economic categories,<sup>21</sup> of which category 1 households (the poorest families) receive full support from the government to join the CBHI, among other types of support. Despite that these programs likely have translated into increased use of health services; cases of acute leukemia may remain under-reported.

Moreover, though ALL patients in Rwanda typically receive chemotherapy, the prognosis is worse than in Western countries.<sup>7,22</sup> Furthermore, AML, which is typically only treated palliatively in Rwanda, has a dismal prognosis.<sup>7</sup> The Rwanda non-communicable diseases (NCDs) national strategic plan for 2014–2019 concerning priorities to be addressed includes chronic myeloid leukemia (CML), but not acute leukemia.<sup>23</sup> The suboptimal management of acute leukemia in Rwanda may also contribute to the low utilization of available services, as acute leukemia is not among the 13 priority cancers to be addressed in the 2014–2019 national strategic plan.<sup>23</sup>

From the perspective of spurring further understanding of patients' healthcare-seeking behaviors, healthcare providers' experiences and perceptions on quality of health services and the status of health systems in the field of acute leukemia in Rwanda, we designed an explanatory qualitative research project. Our study aimed at generating new themes and hypotheses to address challenges associated with the timely diagnosis and efficient therapy of acute leukemia in Rwanda.

## Methods

### Study Design

This was a qualitative study using a phenomenological approach.

### Study Sites and Subjects

The study included acute leukemia patients and patients' guardians met at cancer treatment center in Rwanda. In addition, healthcare professionals were interviewed, such as physicians working in district hospitals, oncologists, general pathologists, and hemato-pathologists from referral teaching and specialized hospitals, as well as healthcare administrators from the central government.

### Sampling

The one specialized and three referral hospitals as well as two district hospitals and the central healthcare administration were selected using a purposive sampling technique. In-depth interviews were performed for acute leukemia patients and

patients' guardians selected using convenience sampling technique. Healthcare professionals and administrators were selected using the intensity sampling technique, that is, the selection of information-rich individuals who would provide in-depth information and knowledge on the experience of acute leukemia patients and the existing capacity to manage this group of diseases. The number of participants was determined considering the saturation of ideas for patients, patients' guardians, physicians at district hospitals, and general pathologists. For other healthcare professionals and healthcare administrators, the number was determined by their availability.

## Data Collection Techniques and Procedures

An interview guide was pre-designed and pre-tested to help interviewers to cover important potential themes. The interview guide included main questions as well as probes, and additional probes emerged according to participants' responses. The details of the interview guide used in this study are provided in [Supplementary File 1](#). All the interviews were done face-to-face. Experienced qualitative researchers were involved in data collection and analysis. This study followed the previously documented 32-item checklist of consolidated criteria for reporting qualitative studies (COREQ).<sup>24</sup>

Data collection took place between July and October 2019. Before commencing the interviews, we were provided with an office for interviewing, then enrolled ALL patients (or guardians) receiving treatment. Healthcare professionals and administrators were enrolled at their respective working units. Written informed consent was obtained from the participants. During the interview, an audio recording was performed for participants who accepted it. Two persons conducted the interview, an interviewer and a note-taker (writing down the information that could not be audio-recorded, such as emotions). For those who declined recording, information was documented in writing by two note-takers and their notes were merged into a single file for each research participant. Transcripts were returned to healthcare professionals and administrators for eventual comments and corrections. Healthcare professionals and administrators also got an overview of the findings and provided their feedback.

## Data Management and Analysis

Obtained data were transcribed into text, then translated into English. However, some interviews for healthcare professionals and administrators were conducted in English. The data were analyzed using thematic analysis in order to understand healthcare-seeking behaviors, perceptions of quality of health services, and status of health systems. Data processing included reading, coding, displaying, reducing, and interpreting. The reading and coding were initiated during the data collection. The primary themes and sub-themes were identified through initial coding. Transcription was performed by a trained research assistant and then double-checked by the investigators. The translation was performed by a research assistant proficient in English and Kinyarwanda. Other research assistants then translated the text back to Kinyarwanda again. Investigators double-checked the translation by comparing the information in the original Kinyarwanda data and the information in the Kinyarwanda text translated back from the obtained English text. The quotes included in this paper are representative of all opinions obtained.

## Ethical Considerations

The study was approved by the Institutional Review Board. Authorization was obtained from each participating institution before data collection. Written informed consent was obtained from each research participant. Participation in the study was voluntary and confidentiality of data was strictly maintained. The recorded information was transcribed into anonymous text. The audio recorder device could not be connected to internet and was kept with a security code. Interview notes were anonymously coded; informed consent and interview notes were kept in a secure and locked place. The transcribed and the translated anonymous texts were kept in a password-protected computer.

## Results

### Characteristics of the Research Participants

In total 41 persons were interviewed in this study, as shown in [Table 1](#). Four of the participants were patients, aged 18–36 years, and eight were patients' guardians, aged 26–53 years. There were 29 healthcare professionals and administrators, met at different health facilities and the central healthcare administration.

**Table 1** Characteristics of Research Participants

Category of Participants	Number of Participants
Patients	4
Patients' guardians	8
Oncologists	2
Hemato-oncologist	1
Hemato-pathologist	1
General pathologists	6
Physicians	17
Healthcare administrators	2
Total	41

## Themes and Sub-Themes Identified in This Study

The results were organized into themes and sub-themes, some of which emerged before the implementation of data collection while others were derived from the data. Table 2 summarizes the themes and sub-themes in this study.

**Table 2** Themes and Sub-Themes in the Interviews of Patients/Guardians, Health Professionals, and Health Administrators on the Management of Acute Leukemia in Rwanda

Theme	Sub-Theme	Examples/Causes
Barriers to healthcare-seeking behaviors	Low awareness	Consultation of traditional healers; underestimation of the disease; stigmatization of families with acute leukemia patients; fear of a bad diagnosis.
	Financial accessibility	No health insurance, or co-payment fee.
Healthcare services: quality and contribution to the turn-around time from the first consultation to the beginning of therapy	Poor knowledge of some professionals	Acute leukemia was misdiagnosed as infection and eventually mismanaged.
	Delay to diagnosis	Shortage of specialized health professionals and equipment; recurrent stock-out of consumables.
	Suboptimal disease characterization	Lack of advanced methods for acute leukemia subtyping, such as flow cytometry and genomic landscaping services.
	Lack of some therapeutic services	Lack of targeted therapy, immunotherapy, bone marrow transplantation for ALL; lack of any curative-intent therapy for AML.
	Financial and geographic accessibility	Patients unable to pay for services not covered by health insurance (such as deposit fee, consumables not available in the public health facility, transport for the periodic appointments at oncology facility).
Healthcare system administration	Tedious referral system	Some healthcare professionals are reluctant to refer patients to a higher-level health facility.
		Patients have to go through the full referral system, which is tedious and time consuming.
	Scarcity of guidelines	No protocols for early detection and management of cancer from basic health facilities.
	Lack of training	Healthcare professionals at basic health facilities have little knowledge of acute leukemia.
	Prioritization	Acute leukemia is not included in the priority cancers to be addressed at the national level.

**Abbreviations:** ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia.

## Barriers Preventing Patients with Symptoms of Acute Leukemia from Seeking Healthcare

The most mentioned potential barrier for seeking healthcare was poor knowledge about acute leukemia among patients and/or their families. Many patients thus consulted traditional healers from their communities and used traditional medicines until the treatment failed and the disease reached an advanced stage.

I had been cared for by traditional healers for about 8 months ... when I found that there was no change, but my condition was deteriorating, I went to ... health center ... I was really very ill at that time. Patient 1

According to some participants, this behavior was linked to insufficient knowledge of the existence of leukemia as a disease, a lack of knowledge regarding the availability of acute leukemia treatments in Rwanda, or the idea that they had been bewitched or poisoned.

... The government should sensitize the community to increase the knowledge of the population about these cancers so that they can go immediately to a health facility rather than delaying to the traditional healers as we did ... Patient's guardian 2

In addition, some patients report difficulties to travel the long distances required to get to sites of diagnosis and treatment. Specifically, transport costs for both patients and patients' guardians when they have appointments at the oncology center were mentioned as obstacles. To emphasize this, some participants stated that while the patients had started off treatment being in category 3 of Ubudehe, after a period of time they had spent so much while earning nothing that they fell into category 1 (poor households). A social stigma of exclusion from society was observed in some cases.

... neighbors are fed up with helping us. They stopped helping and even inviting us to their parties. They are asking themselves the reason why we are struggling for the patient with an incurable disease. They observed how we went from Ubudehe category 3 to category 1 and said that if it was them, they should not even go to the oncology center to struggle with an incurable disease ... Patient's guardian 3

The perceptions of healthcare professionals about barriers preventing patients with symptoms of acute leukemia from seeking healthcare are not different from those listed by the patients and patients' guardians.

Some patients come at an advanced stage; they start going to traditional healers thinking about being poisoned. When traditional healers fail, and/or a community health worker (CHW) becomes aware of that sick person, they then come to the health facility. On the other hand, other patients who don't have CBHI or fail to find the co-payment fee, don't come until they become very ill. Physician DH 1

... Some patients start thinking about the transport and how the patient's guardian will live there at ... hospital during diagnosis ... and start thinking about treatment at the oncology center which is far, not even in the center of the country. Some refuse to be referred to there. Physician DH 5

Financial barriers were also mentioned; as some people do not have health insurances and are unable to pay out of their pocket, or even patients with CBHI, are not always able to pay the co-payment fees.

... Some don't have insurances and (cannot) even (pay) co-payment fees, so local administration should work hand in hand with health facilities to help these patients. Physician DH 3

## Observations by the Participants on the Management of Acute Leukemia in Rwanda

The perception from participants was that some healthcare professionals at district hospitals were not conversant with the detection of acute leukemia. Instead, some healthcare professionals at health centers and district hospitals started treating acute leukemia patients for different diseases such as tuberculosis, malaria, or other infections and even gave transfusions to patients several times without improvement. Acute leukemia patients therefore sometimes remained in hospital for weeks or even months without a proper diagnosis instead of being referred to a higher-level health facility.

... But it is not every doctor who can easily identify these symptoms. A patient may visit the hospital up to three times without identifying the disease thinking about something else ... Physician DH 6

... At the district hospital a diagnosis of infection (pneumonia) was made, and antibiotics were given. Then, a diagnosis of malaria was made, and its treatment added to the prior treatment, still without improvement ... Patient's guardian 2

According to healthcare professionals from referral hospitals, most of the patients were referred to the hospital at the end stage. The main reasons were delays in seeking healthcare and a tedious referral system. Additionally, some physicians and laboratory scientists were said to have poor knowledge regarding the features of acute leukemia or the local existence of its therapy. The practice at Masaka district hospital was an exception and serves as a good example of how to timely manage acute leukemia.

What I know, patients go to a health center and receive treatment. When they are challenged, they refer (the patient) to a district hospital .... Usually, the patients reach an oncologist at the end-stage of the disease. Some die before coming there and others die before getting these different services. It is really a long journey and long process too. Oncologist 1

I did not know that leukemia was treated in Rwanda although I was a medical specialist working in a referral hospital until I came to work in Oncology. Oncologist 1

Our procedure, when we suspect leukemia based on clinical manifestations and whole blood count, is that we prepare peripheral blood film slides that we send to Rwanda Military Hospital for interpretation by hematopathologists. They consider that as a referred patient. If PBF suggests leukemia, we refer the patient for bone marrow aspiration and biopsy to confirm the diagnosis of leukemia and possibly treat the patient. That procedure helps the patient to have a timely diagnosis. Physician DH 11

Healthcare professionals and administrators noted that the management of acute leukemia is not adequate due to the low number of hematologists, oncologists, and pathologists in Rwanda. Health professionals have experienced the unavailability of advanced, or even standard, diagnostic facilities and treatment. Sometimes practitioners needed to send specimens out of the country for confirmation of diagnosis.

... the means of diagnosis and treatment of acute leukemia need to be increased and improved, and some of them availed at district hospital instead of referral hospitals only. We still need hematologists, oncologists, even laboratory scientists. ... There is a need for early diagnosis, equipped laboratory with advanced materials such as PCR and flow cytometry, and ultimately the qualified laboratory scientists and trained physician for the detection and early screening. Oncologist 2

Patients also ascertain the tedious referral system as a barrier to a timely diagnosis of acute leukemia. A patient passes through many different health facilities, some of which misdiagnose the disease thus giving inappropriate treatment. Figure 1 shows the referral system described by one patient's guardian regarding what happened to them personally (the patient and the patient's guardian). When the patients are referred to the diagnosing hospitals, the disease is generally very advanced.

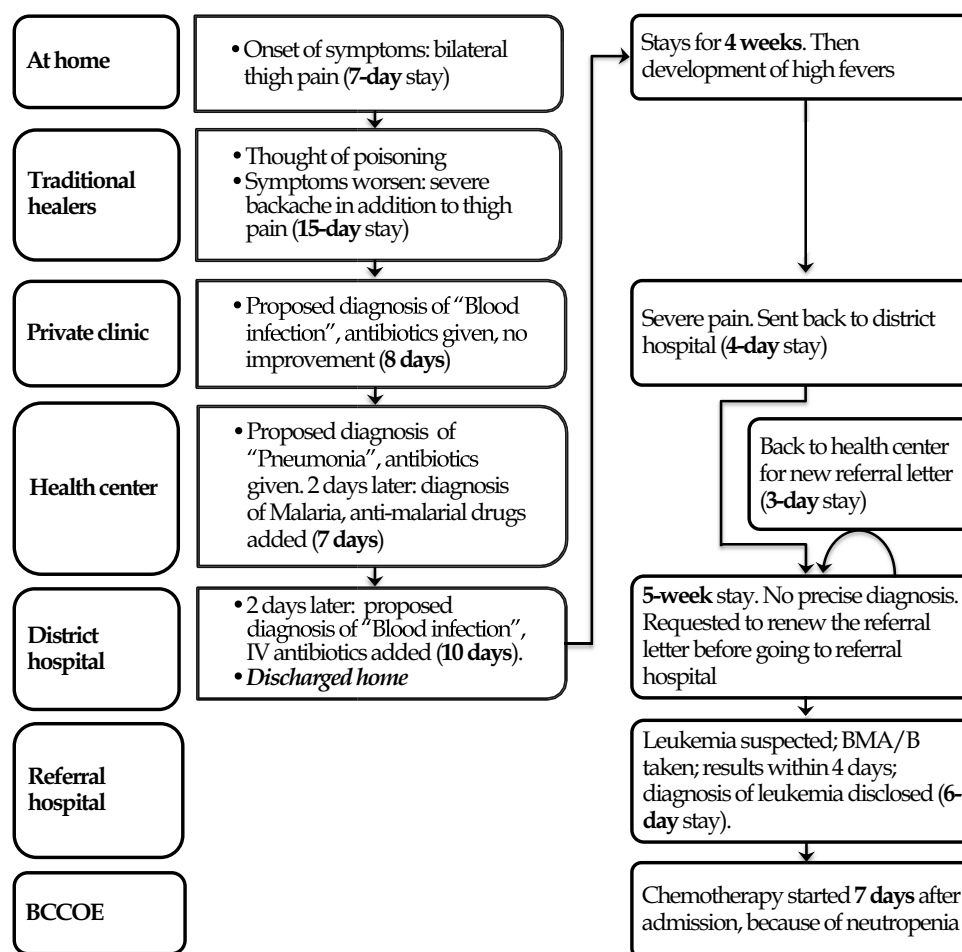
The doctor decided to keep the child at the district hospital. But after time, with the deterioration of the clinical condition, the doctor decided to refer the patient to the referral Hospital. I see that it was late; we should have been sent earlier ... When they decided to refer us, the referral from the health center had expired ..., I went to get a new referral from the health center, came to the district hospital, and got a referral to the referral hospital. Patient's guardian 3

## Existing Capacities in Terms of Diagnosis and Therapy for ALL and AML in Rwanda

### Diagnosis

Patients' guardians, physicians at district hospitals, pathologists, hematologists, oncologists, and healthcare administrators at cancer diagnosis and treatment units confirm that the methods used to diagnose acute leukemia are not adequate. Modern diagnostic methods, such as flow cytometry and molecular testing, are not yet used in Rwanda.





**Figure 1** An example of an ALL patient's journey, from the onset of symptoms to the initiation to chemotherapy.

**Abbreviations:** BCCOE, Butaro cancer center of excellence; BMA/B, bone marrow aspiration and biopsy; IV, intravenous.

The means of diagnosis of acute leukemia in Rwanda include morphology (peripheral blood film, bone marrow aspiration/biopsy) and immunohistochemistry. Procedures such as flow cytometry, cytogenetics, and molecular pathology are not available in our hospitals. Pathologist 4

## Treatment

The available means of ALL therapy is chemotherapy! Bone marrow transplantation is not available. There is no AML curative therapy in Rwanda. AML patients receive palliative care alone inside the country, but those who have financial means go abroad for specific curative therapy. Pathologist 3

The number of doctors who treat cancer in Rwanda has increased, but is still quite small; as of now, there are seven oncologists in the country. The current protocol for ALL treatment in Rwanda is Hunger 3 and 4.<sup>25</sup> If the patient does not achieve complete remission following induction chemotherapy, palliation is the next option.

... We then start consolidation therapy, if remission is achieved (control BMA/B at day 29) ... Currently, Hunger 3 and 4 protocol is followed. But in case of refractory disease, there is a disappointment to medical staff ... Oncologist 1

... There was no single doctor who was trained but now there are almost seven doctors (oncologists) who can treat cancer ... Healthcare administrator 2.

## Recommendations from the Research Participants

Despite various challenges met by patients/patients' guardians, they expressed their appreciation of the customer care they get especially at the Oncology service units.

... I am so grateful for the staff in this ward, for the words of encouragement, for helping us in need, in a few words, for their level of compassion. Patient 4

Some of the participants recommended raising awareness in the community to increase public awareness, and train nurses and doctors in district hospitals on the signs and symptoms of acute leukemia. This can be combined with smoothening the referral system so that when health care providers suspect acute leukemia, they transfer the patient to the specialized hospital as soon as possible.

In addition to promoting early healthcare-seeking behaviors and strengthening the skills of health professionals at all levels to timely detect cases of acute leukemia, we also recommend the ministry of health and stakeholders to smoothen the referral system, avail diagnostic services/infrastructures, and consumables, and include AML among treatable cancers in Rwanda. Pathologist 3

... the government should sensitize the community to increase the knowledge of population about these cancers so that they may go immediately to health facility instead of delaying by going to the traditional healers as we did ... Patient's guardian 6

Healthcare professionals and administrators also suggested that the government should increase the number of specialists with experience in acute leukemia diagnosis and treatments, as well as increase the number of centers for acute leukemia diagnosis and treatment. Healthcare professionals also suggested that diagnosis of acute leukemia should be done at district hospitals.

... Up to now the means of diagnosis and treatment of acute leukemia need to be increased and improved, availed at district hospital instead of only referral hospitals. We still need hematologists, oncologists, pathologists, and even laboratory scientists. Oncologist 2

Other healthcare professionals recommended having advanced equipment in diagnosis and treatment centers; this may speed up the diagnosis and help in the treatment of refractory ALL cases.

I would recommend the implementation of ancillary tests in the diagnosis of acute leukemia such as flow cytometry, cytogenetics, and molecular pathology for better categorization of different subtypes of ALL and AML as recommended by WHO. This will facilitate early diagnosis and better management of patients. Hematopathologist

Participants (patients, guardians and healthcare professionals) requested that the government of Rwanda should help cancer patients to cover all the expenses from the time when the diagnosis of cancer is made.

.... I think it would be good if the Government of Rwanda could issue instructions allowing all cancer patients in Ubudehe categories 1–3 to have free care from the time the diagnosis of cancer is made. At the oncology center, anti-cancer drugs are free, but many expenses cannot be paid for by families. Pathologist 1

## Discussion

The incidence of cancer in Rwanda is likely underreported.<sup>20,26</sup> In accordance, the observed incidence of ALL and AML in Rwanda is low compared to the expected numbers,<sup>7</sup> and it is thus important to identify factors associated with the low detection rate. The purpose of this study was to investigate barriers faced by acute leukemia patients for the timely diagnosis and the treatment of their diseases, as well as to document existing technical and management capacities for diagnostic and therapeutic services for acute leukemia in Rwanda.

Our results imply that poor knowledge regarding acute leukemia is one of the barriers preventing patients from seeking healthcare. Some patients and/or their families assume that their disease may be treated by traditional healers, others suspect that they have been bewitched or poisoned. Similar barriers have been observed in other settings and other types of diseases.<sup>14,18,27</sup> The fear of a severe diagnosis, or of being stigmatized by the community because of an incurable



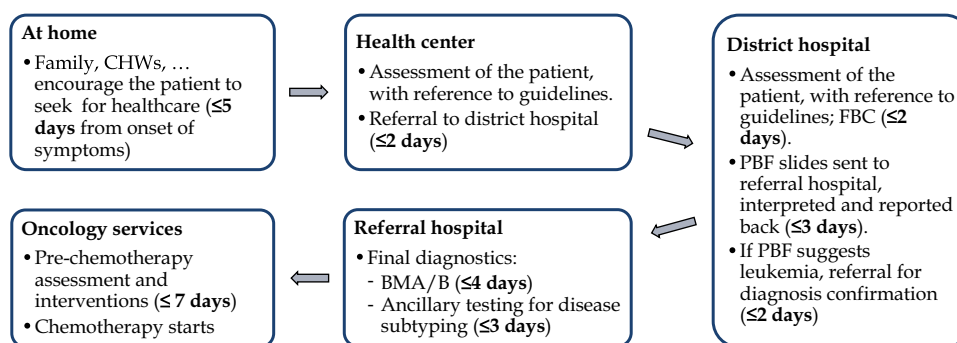
disease, was also mentioned as an important barrier to seeking healthcare. These findings show that it is important to raise awareness within the population regarding acute leukemia, including the value of early diagnosis and that these diseases may be successfully treated. The need to increase cancer education within the population was also recently highlighted in Tanzania.<sup>27,28</sup> Moreover, traditional healers also need to be aware of acute leukemia and other cancers, in order to promptly send patients with symptoms of these diseases to health facilities.

Financial issues were also mentioned by patients and guardians as barriers to timely healthcare-seeking behavior, as well as the geographic accessibility of diagnostic and/or therapeutic services in Rwanda. Although the majority of Rwandans have healthcare coverage through health insurance schemes, there are some who do not, and some members of the CBHI who are unable to pay the co-payment fee, which is 10% of the healthcare costs. In addition, some families have difficulty paying for services not covered by health insurance plans such as transport for patients and guardians and special feeding for patients. Geographical accessibility, availability of services, and financial accessibility and acceptability have been mentioned in other developing countries as barriers to seeking healthcare among impoverished populations.<sup>10,12,13,17</sup> For many patients, costs are unaffordable, and it was proposed that after diagnosis of cancer, cancer treatment should be free for patients in Rwanda, as it is already done in Tanzania since 1993.<sup>27,28</sup> In accordance, as soon as a patient is confirmed to have cancer, costs related to treatment, other investigations, patient's feeding, and hospitalization would be covered by the government.<sup>27</sup> Rwanda has demonstrated the possibility of implementing a free healthcare policy for patients diagnosed with certain diseases. The policy of free healthcare has to a large extent been implemented in Rwanda for patients diagnosed with certain types of diseases such as tuberculosis and human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS).<sup>29,30</sup> In addition, cancer care in Rwanda would benefit from increasing the number and improving the quality of sites offering cancer services. We suggest that increasing awareness of acute leukemia within the Rwandan population, increasing accessibility of cancer clinics, and reducing costs associated with treatment would improve the healthcare-seeking behavior of patients with acute leukemia in Rwanda, and thus improve the detection rate of acute leukemia cases. The quality of customer care at the cancer-treating unit was judged very favorably by patients and guardians. This positive attitude of healthcare professionals is very important in relieving patients' and/or family's stress associated with the diagnosis and/or therapy of cancer.<sup>31–33</sup>

The knowledge of doctors working in peripheral hospitals is likely sub-optimal for the detection of acute leukemia cases. It is known that the training of physicians and nurses for the diagnosis of diseases such as tuberculosis has increased the detection rate of this disease.<sup>34</sup> Based on our experience in Rwanda, the training of health professionals, along with the development of disease detection and diagnosis protocols, has a significant positive impact on timely diagnosis and treatment. Therefore, we assume that training physicians, nurses, and laboratory scientists/technologists in peripheral health facilities to detect acute leukemia will greatly improve the detection of these cases and thereby improve outcomes. Moreover, after realizing that even some Rwandan specialists are not aware of the availability of ALL treatment services in Rwanda, it is obvious that specialists-in-training in Rwanda need to be acquainted with the existing capacities in the management of acute leukemia and other cancers in Rwanda.

The Government of Rwanda had planned that, during the period 2014–2019, the issue of shortage of specialists in the area of cancer should be addressed.<sup>23</sup> Some of the strategies included local training of medical specialists through the human resources for health (HRH) program.<sup>35,36</sup> However, the above-mentioned strategic plan focused on types of cancer other than ALL and AML, because these diseases were not included among the 13 types of cancer considered as priorities in Rwanda.<sup>23</sup> Moreover, that strategy did not include the training of healthcare professionals at the district hospital level. The shortage of trained medical specialists and the lack of the training of health professionals at the district level are barriers to the optimal detection of cancer cases,<sup>37</sup> including acute leukemia. We argue that acute leukemias are serious diseases that deserve to be considered for inclusion among the prioritized types of cancers in the next national strategic plan and policies on non-communicable diseases.

The quality of healthcare services depends not only on the knowledge and skills of healthcare professionals but also on the continuous availability and accessibility to standard infrastructures and procedures for the diagnosis and treatment of diseases.<sup>9,13,19</sup> In Rwanda, the diagnostic capacity for subtypes of ALL and AML is sub-optimal as compared to the standard diagnostics established by the World Health Organization (WHO).<sup>38</sup> This may negatively



**Figure 2** Proposed roadmap for management of a patient with suspected acute leukemia, from onset of symptoms to the initiation of chemotherapy. **Abbreviations:** BMA/B, bone marrow aspiration and biopsy; CHWs, community health workers; FBC, full blood count; PBF, peripheral blood film.

impact the standards of care. The absence of potentially curative therapy for AML cases such as bone marrow transplantation are important issues to address. Furthermore, the referral system in Rwanda was alleged by patients and guardians to partly delay the care of patients and is thus an important concern. We suggest that the Government should plan for a re-evaluation of the referral system, and plan for increasing the awareness of acute leukemia among healthcare professionals at peripheral levels, which should improve the detection rate and timely diagnosis of acute leukemia cases in Rwanda.

Based on the observations from this study, we propose the roadmap shown in Figure 2 for the management of acute leukemia in Rwanda. The proposed roadmap implies that the patient and those around them (for example family members and community health workers) should ensure that the patient consults the primary healthcare facility on time. It also involves developing guidelines for cancer detection and management tailored to each level of the health system, starting with the health center level. Likewise, the district hospital should work with the supervising referral hospital to have the peripheral blood film (PBF) slides screened on time prior to the eventual referral of the patient to a referral hospital in case the PBF is suggestive of leukemia. Also, all referral hospitals should have access to comprehensive diagnostics for leukemia, to enable rapid initiation of therapy.

## Conclusion

The results of this study imply that an important factor contributing to the apparently low incidence of acute leukemia in Rwanda is a low detection rate which is caused by a delay in healthcare seeking behavior among many Rwandans, a tedious referral system, unsatisfactory financial accessibility, and sub-optimal cancer diagnostic services. The low detection rate and the long time to diagnosis in combination with suboptimal therapeutic services, have negative impact on the patients' health outcomes. A comprehensive set of strategies is needed to address all these issues, as highlighted in this work, to improve the detection, optimal disease characterization, and implementation of improved therapies in Rwanda.

## Abbreviations

ALL, acute lymphoblastic leukemia; AML, Acute myeloid leukemia; BM, bone marrow; BMA/B, bone marrow aspiration and biopsy; CBHI, community-based health insurance; CHW, community health worker; CML, chronic myeloid leukemia; DH, district hospital; FBC, full blood count; HRH, human resources for health; NCD, non-communicable disease; PBF, peripheral blood film; WHO, world health organization.

## Data Sharing Statement

The datasets generated during the current study are not publicly available due the ethical restrictions but are available from the corresponding author on reasonable request.

## Ethics Approval and Consent to Participate

The study was approved by the Institutional Review Board (IRB) of the University of Rwanda College of Medicine and Health Sciences (UR-CMHS), approval number 315/CMHS IRB/2019. Authorization was obtained from each participating institution prior to data collection. To ensure confidentiality, data were deleted from audio recorder devices immediately after their transfer to the computer. The information provided by the participants was strictly treated as confidential. Written informed consent was obtained from all the participants in the study; the informed consent included information to have anonymized responses. The study was conducted in accordance with the Declaration of Helsinki.

## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis, and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agreed to be accountable for all aspects of the work.

## Disclosure

The authors declare no competing interests. The views expressed in this article are those of the authors and not the policies or views of affiliated institutions.

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