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ORIGINAL RESEARCH

Aplastic Anaemia Disease Burden From the Patient Perspective and Quality of Life in Zimbabwe by A. *Maramba and J. Mupini*

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Purpose: Aplastic Anaemia (AA) is a critical haematological disorder characterized by pancytopenia and marrow hypoplasia. It is generally regarded as a rare disease albeit with multiple symptoms. The aim of the study was to get the patients' perspective to evaluate the disease burden and their knowledge, attitude, practices, and adherence to treatment.

Patients and Methods: This qualitative cross-sectional study was conducted at the Parirenyatwa Group of Hospitals in Harare, Zimbabwe, to investigate patients' perspectives on their knowledge, attitudes, practices and disease burden regarding AA.

Results: Eleven participants diagnosed with AA via bone marrow biopsy were recruited between November 2022 and May 2023. A structured, ethically approved questionnaire was used to gather data on demographics, clinical status, treatment experiences, and overall disease knowledge. Results showed that respondents generally possessed a robust understanding of their condition; however, financial constraints significantly hindered access to appropriate treatment options, including potential curative therapies such as hematopoietic stem cell transplantation. Zimbabwean healthcare faces profound challenges, with less than 5% of patients receiving appropriate therapy within the first year of diagnosis.

Conclusion: This study underscores the urgent need for enhanced patient support systems and policies to improve healthcare access for individuals with AA in Zimbabwe. Recommendations include the development of targeted awareness initiatives and supportive resources to elevate the quality of life for patients with aplastic anaemia.

Keywords: aplastic anaemia, knowledge, attitude, practice, disease burden, treatment

Introduction

Aplastic anaemia (AA) is a rare but life-threatening haematological disorder characterized by a failure in haematopoiesis leading to the severe reduction of red blood cells, white blood cells, and platelets. This results in pancytopenia, an array of clinical manifestations, including anaemia-related fatigue, heightened susceptibility to infections due to leukopaenia, and increased bleeding risk stemming from thrombocytopaenia.[1] The global incidence of AA is estimated at 2–8 cases per million people annually, with variations depending on geographic and demographic factors.[2,3]

The etiology of AA can be divided into inherited and acquired categories. Inherited AA occurs due to a random gene mutation that is passed from parents to their children. Acquired AA can occur due to exposure to various environmental factors, including radiation, toxic chemicals (eg, benzene, pesticides), and certain medications (eg, chloramphenicol, gold salts).[4,5] Environmental factors specific to sub-Saharan Africa, including endemic infections and nutritional deficiencies, may further exacerbate the risk of developing AA.[6] The mechanism of immune-cause involves decreased regulatory T-cells, which result in increased interferon gamma levels by gene T-bet (a transcription factor and regulator of Th1). This results in reduced formation of haematopoietic stem cells in the bone marrow by inducing apoptosis of CD34+ cells. CD34+ cells function as cell-cell adhesion factor and mediates the attachment of stem cells to the bone marrow

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extracellular matrix.[7] Zimbabwe is one of the countries highly burdened by HIV and AA has been reported as a complication of HIV infection.[8] This can be a result of damaged bone marrow due to weakened immune system. There is also persistence of pancytopaenia in individuals with advanced HIV disease and poor prognosis, which can lead to development of aplastic anaemia.[9] Medications used to manage HIV have been associated with leading to AA, although in rare conditions.[10]

It is important to recognize that AA is not solely a diagnosis of exclusion but rather requires careful differential diagnosis to distinguish it from aplastic crises due to other disorders such as hereditary spherocytosis and hyperplastic bone marrow syndromes.[11] The diagnosis of aplastic anaemia usually involves evidence of peripheral blood cytopaenia and ineffective haematopoiesis. Commonly performed tests include; full blood count (FBC), reticulocyte count (to determine number of immature cells) and bone marrow biopsy (to check for the number, size, and maturity of blood cells). Other more specific tests such as; the paroxysmal nocturnal hemoglobinuria (PNH) flow cytometric based tests that directly demonstrate the disease phenotype, ie, GPI-linked antigen deficiency (CD55, CD59 and FLEAR- fluorescent aerolysin) and sequencing of PIG-A gene for mutations can be performed to confirm the disease.[12]

In Zimbabwe, research on the prevalence of AA is sparse and this could be a result of the disease being under-diagnosed and the healthcare system struggling with significant barriers. At present, due to limited resources less than 5% of patients with newly diagnosed AA receive appropriate treatment within one year, often due to the high costs associated with advanced therapies.[3] The cost of medications, procedures and the absence of a national donor registry contribute to the challenges patients face in receiving timely care.

Current management strategies for AA include immunosuppressive therapies such as antithymocyte globulin (ATG) and cyclosporine. Other options include transfusions of packed red blood cells and platelets and preventive antibiotic therapy. However, emerging treatment options provide additional avenues for care. Eltrombopag, a thrombopoietin receptor agonist, has demonstrated efficacy in increasing platelet counts in patients with both primary and secondary AA, and single-agent cyclosporine is also used for selected patients.[5] Bone marrow transplant from a suitable donor is a more effective option for patients below 40 years.[13] Despite these advancements, access to treatment remains severely limited in Zimbabwe due to high cost of the medications and systemic inefficiencies, resulting in high morbidity and mortality rates.

Although significant morbidity is associated with untreated AA, there remains a critical gap in literature regarding the experiences and perspectives of patients within the Zimbabwean healthcare context. By focusing on patient perspectives regarding their knowledge and attitudes towards AA, this study seeks to illuminate essential themes relevant to improving care and establishing effective support systems for affected individuals.

Materials And Methods

Study Design

This qualitative cross-sectional study was implemented at the Parirenyatwa Group of Hospitals, which serves as a primary healthcare facility in Harare, Zimbabwe. The study was approved by the University of Zimbabwe and Parirenyatwa Group of Hospitals Joint Research Ethics Committee (Ref: JREC382/2022).

Participants

A total of 11 patients diagnosed with aplastic anaemia were enrolled in this study between November 2022 and May 2023. The inclusion criteria were defined as follows: individuals aged 16 to 40 years, confirmed diagnosis of aplastic anemia via bone marrow biopsy based on World Health Organization criteria. The criteria say that for peripheral blood counts there should be at least two of the following:

- Haemoglobin <10.0g/dL
- Platelet count $<50x10^9$/L
- Neutrophil count $<0.5x10^9$/L

For bone marrow biopsy, bone marrow cellularity should be <30%. Participants who were able to communicate in English were recruited through the haematology clinic within the hospital, emphasizing the need to capture diverse patient experiences within the phase of disease management. The age range of 16 to 40 years was selected because it encompasses both younger individuals and those approaching the upper limit for haematopoietic stem cell transplantation eligibility, where being under 40 years of age is imperative due to improved outcomes associated with younger transplant recipients.[13]

Sample Size Calculation

As this study focused on qualitative analysis, the sample size was based on the principle of data saturation. Previous literature indicates that qualitative studies often reach meaningful conclusions with a sample size of fewer than 15 participants.[14] The decision to enroll 11 participants was therefore deemed appropriate, and it allowed for a rich exploration of the diverse perspectives concerning living with aplastic anaemia.

Data Collection

Data were collected using a structured and validated questionnaire that was specifically created for this study.[15] Having a structured questionnaire is crucial because it helps maintain consistent data collection among all participants, which boosts the reliability of the results.[16] This survey was developed in collaboration with healthcare professionals and patient advocacy groups to ensure that it was relevant and valid, as including various stakeholders helps reduce bias and aligns the tool with the needs of the target audience.[17] Before the main study, a pilot test was carried out with five patients at Parirenyatwa Hospital to enhance the clarity of the questions and improve the overall flow based on their feedback.[18] Conducting a pilot test is essential in research because it helps identify any potential problems and ensures that the questionnaire effectively gathers the necessary information.[19]

The survey was made up of distinct parts which are:

a. Information about the population: Age, sex and religion.
b. Medical condition: Haemoglobin levels, neutrophil counts, platelet counts, record of blood transfusions, HIV status and year of diagnosis.
c. Knowledge and Attitudes: A 5-point Likert scale was used to assess participants' opinions and perceptions on how AA affected their quality of life, treatment adherence, and understanding of their condition. The scale varied from 1 (strongly disagree) to 5 (strongly agree), encouraging detailed responses.[20]
d. Clinical Data: Relevant haematological parameters were collected from electronic medical records for clinical analysis.

The blood levels assessed at the time of diagnosis were:

i. Haemoglobin
ii. Neutrophil count
iii. Platelet count

Religious Affiliation as a Variable

The inclusion of religious affiliation was based on literature suggesting that religious beliefs can significantly impact health-seeking behaviors, coping mechanisms, and overall quality of life in patients with chronic illnesses.[21]

Data Analysis

Descriptive statistical analysis was performed using Microsoft Excel and SPSS Version 25 (IBM Corp). Categorical variables were presented as frequencies and percentages, while continuous variables such as blood counts were summarized as means and standard deviations. Qualitative responses were subjected to thematic analysis, enabling identification of key ideas and repeated patterns related to patient experiences with aplastic anemia.

In this study, both categorical and continuous data analyses were conducted to assess participant responses regarding aplastic anemia, supplemented by qualitative analysis of open-ended feedback.

Categorical Data

For categorical data, frequency and percentage distributions were calculated to evaluate demographic characteristics and responses to knowledge and attitude questions. The frequency distribution involved counting participants in various categories (eg, gender, age group, religious affiliation), providing insights into the demographic profile of the study population.[22] By calculating the percentage of participants within each category, we enhanced data interpretability. For example, we reported the proportion of respondents who agreed or strongly agreed with statements concerning their understanding of aplastic anemia and adherence to treatment, ensuring clarity in presenting their perspective.[23] These analyses not only summarized the characteristics of the sample but also provided a foundation for further statistical inquiry.

Continuous Data

Continuous data analysis focused on critical haematological parameters, including haemoglobin levels, neutrophil counts, and platelet counts. Mean values were computed to represent the central tendency of these clinical markers, which is vital for understanding average levels among participants.[24] Additionally, median values were calculated to provide insight into the midpoint of distributions, which is particularly useful in identifying skewness or outliers in the dataset.[25] The ranges (minimum and maximum values) of these continuous variables highlighted the variability in clinical parameters, reflecting the extent of haematological conditions within the cohort.[26] Together, these statistical analyses offered a nuanced understanding of the health status of individuals diagnosed with aplastic anaemia, pointing to potential areas for patient management improvement.

Qualitative analysis involved exploring themes from participants' open-ended responses, enriching our understanding of their experiences and perceptions. Responses were systematically coded into categories, allowing for the identification of recurring themes within the narratives.[27] Multiple reviewers undertook independent coding to enhance reliability. Key themes were then derived through thematic analysis, addressing major issues such as participants' awareness of aplastic anemia, barriers to treatment, and support needs. This approach ensured a thorough understanding of patient experiences while emphasizing critical insights that might have remained unnoticed in a purely quantitative assessment.[28] To uphold analytical rigor, the review of themes utilized an iterative process that permitted researchers to refine and revisit themes based on the depth of participant responses.[29]

Ethical Considerations

This study was conducted in compliance with the Declaration of Helsinki, ensuring that ethical principles for medical research involving human subjects were meticulously followed. The research protocol was approved by the University of Zimbabwe and the Parirenyatwa Group of Hospitals Joint Research Ethics Committee (Ref: JREC382/2022). Furthermore, verbal informed consent was obtained from participants who had been discharged from the hospital, which was deemed acceptable and approved by the ethics committees. This process ensured that participants were fully informed about the study's aims, procedures, risks, and benefits before agreeing to participate.

Results

Demographic Characteristics

A total of 11 participants were successfully surveyed. The demographic data is shown on Table 1 which summarizes the demographic characteristics of the eleven participants diagnosed with aplastic anemia. The study comprised both male and female participants with varying age groups and a singular religious affiliation.

Gender Distribution

Female Participants: 7 (63.6%)
Male Participants: 4 (36.4%)

Table 1 Demographic Characteristics of Participants

Demographic Feature	Variables	Frequency	Percentage (%)
Gender	Male	4	36.4
	Female	7	63.6
Age Group	16–25	8	72.7
	26–35	3	27.3
Religion	Christianity	11	100

Notes: The demographic details represent the cohort of 11 participants who were surveyed.

Age Group

Ages 16–25: 8 participants (72.7%)
Ages 26–35: 3 participants (27.3%)

Religious Affiliation

Christianity: 11 participants (100%)
Other Religions: 0 participants (0%)

Clinical Status and Treatment Received

Descriptive data on clinical parameters included a mean haemoglobin level of 11.9 g/dL (SD ± 1.2 g/dL), with a range of 10.0 g/dL to 13.0 g/dL. The mean absolute neutrophil count was 1,200 cells/μL (SD ± 500 cells/μL), and platelet counts averaged 80,000 cells/μL (SD ± 30,000 cells/μL) at diagnosis as shown in Table 2.

Method of Treatment (Treatment Modalities) and Patients Insights

Participants in the study shared various treatment approaches for aplastic anemia as shown in Table 3. Notably, 9 out of 11 participants (82%) mentioned that they had received blood transfusions. Furthermore, a group, consisting of 6 participants (55%), reported that they had undergone immunosuppressive therapy, using medications like anti-thymocyte globulin (ATG) and cyclosporine. Additionally, 2 participants (18.2%) were prescribed Eltrombopag, a drug that acts as a thrombopoietin receptor agonist and 1 person had not received any treatment.

To gain insight into how patients view their condition, a 5-point Likert scale was used. The results in Table 4 showed that 6 participants (54.5%) strongly believed that knowing about their condition was important, while 3 participants (27.3%) agreed, and 2 participants (18.2%) were neutral. A notable 82% of participants expressed that adhering only to prescribed medications was vital for achieving successful treatment results. The other 18% took herbs as treatment.

On the other hand, the study also revealed significant obstacles to accessing healthcare. Specifically, 27% of participants reported that they missed medical appointments because of financial issues as shown in Table 5.

Table 2 Clinical Parameters at Diagnosis

Clinical parameter	Mean (sd)	Median	Minimum	Maximum
Haemoglobin (g/dL)	11.9 (±1.2)	11.8	10.0	13.0
Neutrophil (cells/μL)	1,200 (±500)	1,150	600	1,800
Platelet (cells/μL)	80,000 (±30,000)	75,000	20,000	120,000

Notes: Clinical parameters represent the average values observed in participants at the time of diagnosis. Mean values are reported with standard deviation (SD).

Table 3 Treatment Modalities Received by Participants

Treatment Type	Frequency	Percentage (%)
Blood Transfusion	9	82
Immunosuppressive Therapy (ATG, Cyclosporine)	6	55
Eltrombopag	2	18.2
No Treatment	1	9.1

Notes: This table summarizes the treatment modalities received by participants with aplastic anaemia. The frequencies reflect the number of participants who received each treatment type.

Table 4 Participants' Understanding of Aplastic Anemia

Understanding Level	Frequency	Percentage (%)
Strongly Agree	6	54.5
Agree	3	27.3
Neutral	2	18.2
Disagree	0	0
Strongly Disagree	0	0

Notes: This table summarizes participants' opinions on the importance of understanding their condition based on a 5-point Likert scale. Percentages reflect the proportion of participants responding in each category.

Qualitative Findings (Thematic Analysis Overview)

The thematic analysis of qualitative responses identified several significant themes related to the experiences of individuals diagnosed with aplastic anemia. These themes are summarized as follows.

Understanding of the Condition

A considerable number of participants (6/11; Figure 1) indicated that they possessed a solid understanding of aplastic anemia. This knowledge was largely derived from information provided by healthcare professionals, along with personal research conducted through online resources. Participants highlighted the critical role of both professional medical advice and self-directed learning in enhancing their comprehension of the disease.

Table 5 Barriers to Treatment

Barrier to Access	Frequency	Percentage (%)
Financial Issues	10	90.9
Travel Issues	3	27.2
Medication Availability	9	81.8
Emotional Support	4	36.3
No Significant Barrier	2	18.1

Notes: This table reflects barriers faced by participants in accessing treatment. The listed issues are based on participant responses regarding significant challenges encountered.

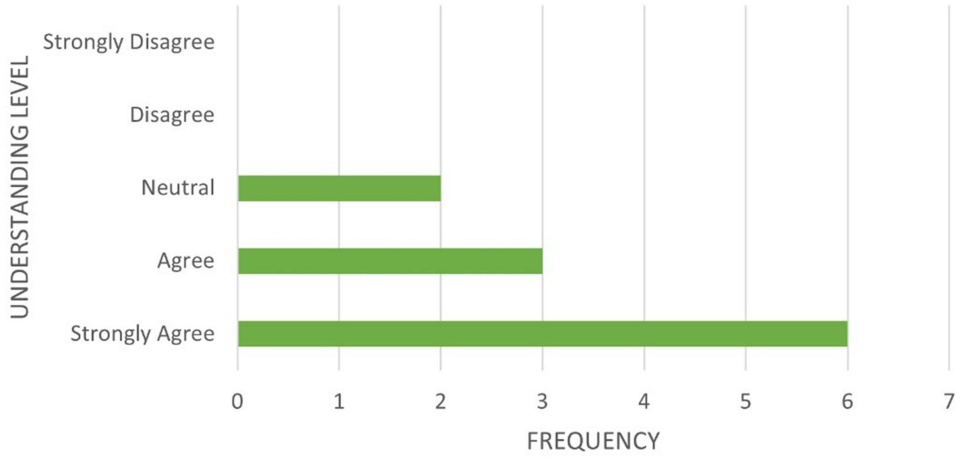

Figure 1 Understanding of condition.This figure depicts the participants' understanding of aplastic anaemia. It shows the distribution of responses to the statement regarding understanding their condition, categorized as Strongly Agree, Agree, Neutral, Disagree, and Strongly Disagree.

Economic Challenges

Economic challenges surfaced as a major theme, with numerous participants noting that the expense of medications created a significant obstacle to following prescribed treatment plans. The discussions revealed worries about the affordability of essential therapies and the potential adverse effects this could have on their overall health.

Demand for Support Networks

Participants conveyed a strong desire for community support services to assist them throughout their treatment processes. The findings emphasized the emotional difficulties linked to managing a chronic illness and the perceived benefits of peer support in reducing feelings of loneliness and anxiety. This expressed need for collaborative support systems highlights a critical area for potential intervention and resource development.

Discussion

The present study investigated the knowledge, attitudes, and experiences of individuals diagnosed with aplastic anemia in Zimbabwe. In the present study there were notably more females than males (Table 1) and this could be due to the health seeking behaviours of females. However other studies have demonstrated that males were associated with worse outcomes than females, possibly due to differences in immune response, genetics and hormonal factors.[30,31] The results show that the majority of participants were young, predominantly in the 16–25 age group (Table 1). They all confirmed that they had been diagnosed within three years of participating in the study, which suggests that these were most likely acquired aplastic anaemia because most cases of acquired aplastic anaemia affect older children, teenagers or young adults.[5,32,33] The observation that all participants had been diagnosed in three years demonstrates that individuals suffering from aplastic anaemia may be having shortened survival rates after diagnosis because of lack of funds to get the proper treatment. Bone marrow transplant was not available at Parirenyatwa Group of Hospitals and patients had to travel to other countries which the patients could not afford. The study consisted entirely of Christian participants. Religion has impact on approaching treatment and support procedures.

Concerning the clinical parameters reported (Table 2), the mean haemoglobin level of 11.9 g/dL aligns with existing literature that documents range often seen in patients undergoing therapy for aplastic anemia.[34] Most of the participants in the study were already getting packed cells during the period of data collection hence they presented with mild anaemia. However, the average neutrophil and platelet counts were notably low, suggesting that while some patients received treatment, there remains a high prevalence of cytopaenia, which is characteristic of the disease and reflects the need for early intervention and continuous management strategies. Regarding HIV, although the condition is highly prevalent in Zimbabwe and has been associated with various haematological manifestations, the absence of HIV-positive

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patients in this study limits the ability to draw any conclusions regarding the disease's interaction with aplastic anaemia within this patient population. Future studies should explore the broader implications of HIV within haematological contexts to better understand its impact on disease management and patient outcomes.[35]

The findings indicate that most participants exhibited a sound understanding of their condition (Figure 1; Table 4), underscoring an essential aspect of managing chronic diseases. Effective patient education and health literacy are crucial, as previous studies have demonstrated a direct correlation between patient engagement and improved health outcomes.[23] Despite this knowledge, the results highlighted significant barriers faced by patients in accessing treatment (Table 5), particularly financial constraints, which is consistent with findings reported in similar studies from low-resource settings.[3] Participants in our study voiced a clear desire for improved support networks and community resources, reflecting a gap in current healthcare services. While individuals with aplastic anemia often benefit from social and psychological support systems,[36] such frameworks are notably lacking in Zimbabwe. The study also indicates that more than 27% of participants missed medical appointments due to financial issues, emphasizing the urgent need for comprehensive social care strategies that encompass both psychological support and financial assistance for affected individuals.

Furthermore, the complexity of healthcare access and service provision in Zimbabwe cannot be overlooked. Current estimates suggest that less than 5% of patients with newly diagnosed aplastic anemia receive timely and appropriate care.[3] This staggering statistic indicates systemic inadequacies requiring urgent reforms to the healthcare framework, enhancing treatment access and patient education, and establishing support initiatives tailored to the needs of individuals living with this condition.

Limitations of the Study

Significant limitations exist in this study, particularly concerning the small sample size, which restricts the generalizability of findings. This research should be viewed as an exploratory pilot study, establishing a foundation for further research and potential development of support programs specifically designed for patients with aplastic anemia in Zimbabwe. Larger, multi-center studies may yield statistically robust data to substantiate these initial findings and inform policy improvements.

Conclusion

Patients indicated a significant demand for improved support networks. Emotional and psychological assistance plays a vital role in managing chronic conditions, and the lack of such systems in Zimbabwe represents a crucial area for improvement. Developing community support services could greatly reduce the feelings of isolation and anxiety that these patients face, thereby enhancing their overall well-being.

While this research offers important insights into the experiences of patients with aplastic anemia, it is essential to recognize its limitations, particularly the small sample size, which limits the applicability of the findings. This study should be considered a preliminary step, setting the stage for future research that includes a larger participant group and delves deeper into the healthcare experiences of individuals with aplastic anaemia.

In our views from this study, comprehensive healthcare reforms are essential to enhance treatment access and create supportive environments for those affected by aplastic anemia. By advocating for policy changes, establishing multi-disciplinary support networks, and improving educational initiatives tailored to patient needs, we can more effectively address the specific challenges faced by this population. This collaborative strategy will promote better health outcomes and improve the quality of life for individuals living with aplastic anemia in Zimbabwe and beyond.

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Disclosure

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