

CML Patient Perspective Africa and The Middle East

CML Patient Advocates Network commissioned a survey to gather data on the Africa and Middle East CML patient community's perspective towards their journey and experience with CML.

The perspective shared should contribute towards the understanding of the challenges faced as expressed by the patients and should contribute towards the development of intervention programs aimed at addressing the needs of this community.

Contributors

The survey was distributed through the CML patient network organizations based in the AME region.

Responses were received from 18 countries over a period of 6 weeks.

Algeria, Egypt, Ethiopia, **Ghana**, Iraq, Madagascar, Mali, **Morocco**,
Nigeria, Palestine, Qatar, Senegal, South Africa, **Sudan**, Togo, Uganda,
Yemen, Zimbabwe.

Total Responses Received = 278

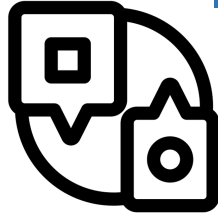
**Most responses received from Ghana, Morocco, Nigeria, and Sudan.*

Participant Demographics



117 Female

162 Male



The survey was available in 3 languages; English, French and Arabic

200 English Responses Received

42 Arabic Responses Received

36 French Responses Received



The eldest responded is **82 years** of age and the youngest **10 years** old.

The majority of responses were received from the cohort of 1980-1989 (79 responses) followed by the grouping from 1970-1979 (60 responses)

= **Age group 40's and 50's**

74% of respondents have tertiary qualifications.

17% of respondents have a high school qualification

5% of respondents have a primary school qualification



Signs and symptoms

88% of patients reported seeking medical care for symptoms presented prior to diagnoses.

12% of patients reported no symptoms at time of diagnoses.



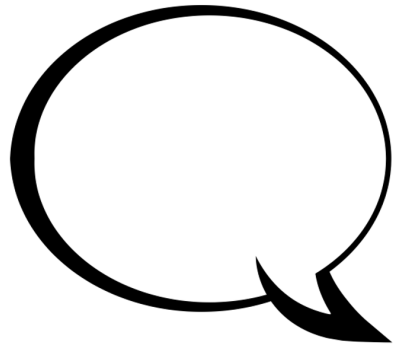
The following symptoms, at the time of diagnoses, were the most reported by the respondents.

Swollen Spleen/ Splenomegaly – **60** mentions

Fatigue – **49** mentions

Weight Loss – **49** mentions

Fever – **31**



Less reported symptoms include:

- Recurring malaria and typhoid
- Vomiting
- Priapism
- Dark blotches on skin

Diagnosis.

Only **41** from the total of 278 respondents did not make any financial contribution towards their diagnostic test.

Average cost for confirmation of disease
USD268

Most expensive reported cost
USD1500



66%

Of respondents had to borrow money, or fundraise, to pay for a diagnostic test


99 Respondents received feedback within **1 week** of testing.
151 Respondents waited longer than **2 weeks** for feedback following testing.
28 Respondents had to wait longer than **1 month** for feedback following testing.

Reaction to the diagnoses.

“Very worried and thinking of imminent death”

-54 year old patient from Senegal, diagnosed 7 years ago.

scared devastated
shock
sad fear
death
confused

Very bad sense. I felt that my life has ended specially since the diagnosis was 20 days before my wedding 

- 34 year old patient from Sudan, diagnosed 3 years ago.

I had no idea what CML meant. I was 14 years old.

21 year old patient from Nigeria, diagnosed 7 years ago.

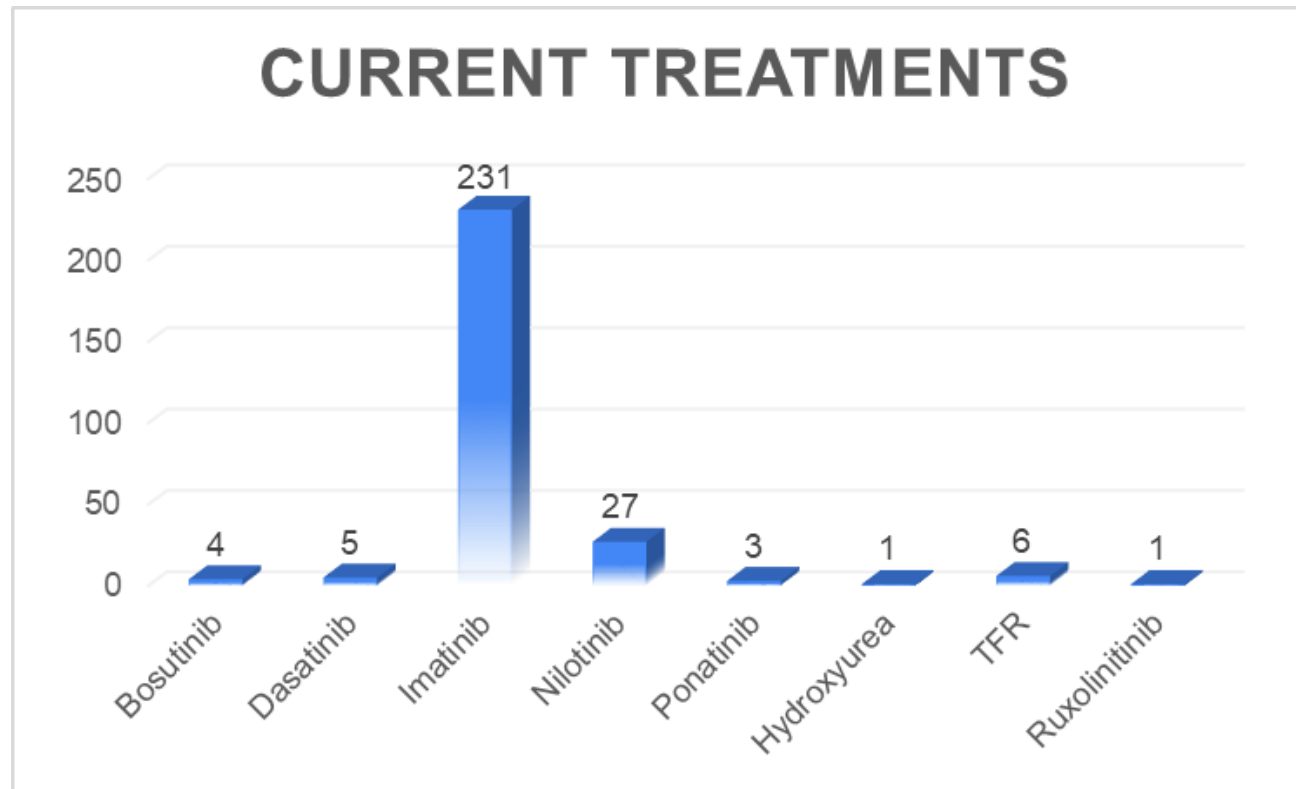
It's an indescribable feeling, A very difficult psychological state, especially because I have small children.

33 year old patient from Palestine, diagnosed 5 years ago.

Treatment.

1989	1
1997	1
1999	1
2000	2
2001	1
2002	4
2003	3
2004	4
2005	4
2006	5
2007	4
2008	9
2009	11
2010	12
2011	7
2012	10
2013	21
2014	25
2015	20
2016	23
2017	34
2018	24
2019	31
2020	14
2021	7

Year of reported diagnosis



Longest reported time on treatment is **19 years** (3 respondents) on imatinib.

62 respondents reported receiving **hydroxyurea** as treatment prior to current treatment.

44 respondents reported receiving **imatinib** as treatment prior to current treatment.

3 respondents reported receiving **interferon** as first treatment prior to current treatment.

Journey to treatment.

2 Respondents visit the clinic for follow-up and to collect medication **bi-weekly**

46 Respondents visit the clinic for follow-up and to collect medication **monthly**

179 Respondents visit the clinic for follow-up and to collect medication **every 3 – 4 months.**

46 Respondents visit the clinic for follow-up and to collect medication **every 4 -6 months**

5 Respondents visit the clinic for follow-up and to collect medication **once every year.**

70 Of the respondents travel a distance of **more than 500km (310mi)** to reach the clinic. The furthest distance reported is over 1000km (621mi) It takes the responders several days to complete. Only 12 respondents reported on returning home on the same day, others have to stay over and cover the cost of accommodation.

“Fear of insecurity, accidents, kidnapping, bad roads, long journey, funds for travelling is the biggest challenge”

“At times your date for the visit will come and you don't have money to attend. And when you don't attend on that day and go on the following week ,they sack you and give you another date “

“I have to have one week to do that. The impact is there but the drugs are worth it.”

“There is always tension because of the insecurity on the road”

“It's a 3 days journey and I am absent from work for that long”



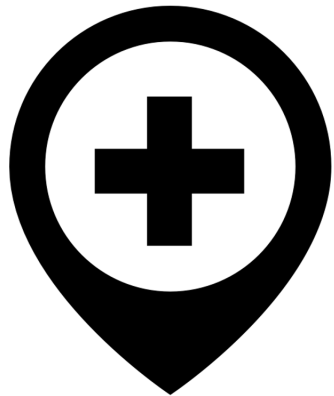
At the clinic.

Most respondents, **176** reported spending between **1 -3 hours** at the clinic.

54 respondents spent between **4 -6 hours** at the clinic on follow-up.

41 Respondents spent less than an hour at the clinic during follow-up

7 Respondents report spending **more than 6 hours** at the clinic.



269 Respondents confirm that a **full blood count** is conducted as part of their monitoring and follow-up with **108** respondents also undergoing a **PCR**.

14 Respondents reported that an **electrocardiogram** was part of the tests during follow-up and **7** respondents reported **sonogram** as part of their monitoring routine.

The cost of consultation and testing varies depending on type of testing done.

Most expensive monitoring cost reported is USD660 which included FBC, PCR and ECG

Real Life.

I often run out of medication because I do not have the money to purchase — Reported by **17 respondents**

157 Respondents reports missing 1 dosage of medication because they forgot to take their medication

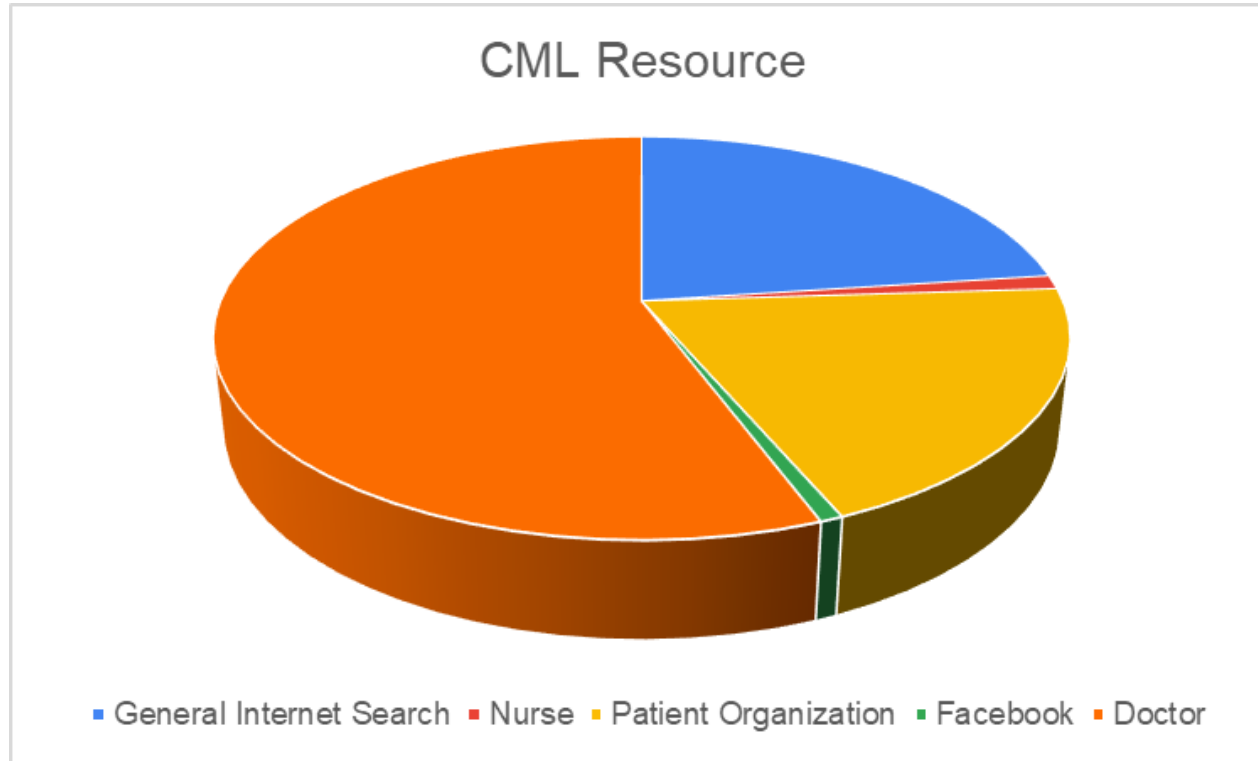
When I miss a dosage it is because the medication made me feel unwell — Reported by **29** respondents

“I may be out of money for food, that would make me miss my dosage”

5 Respondents mentioned missing a dosage due to lack of access to food as they usually take their medication with a meal.



Let's talk about CML.



Most respondents relied on their **doctor** for information about CML. **General internet searches** followed as second resource followed by the **patient organization**.

63% Of respondents want to have one-on-one discussions with their physicians about CML

54% Of respondents want to be engaged in group sessions sharing disease information

51% Of respondents would like to receive reading material about CML

54% Of respondents would like to receive CML information in the format of videos.

Respondents noted preference to receiving disease information via email, mobile messaging applications and social media platforms.

Let's NOT talk about CML.

264 Respondents confirm that their family is aware that they have CML however **147** respondents noted that they will not mention this to the general community.

Most reported reason for not disclosing disease status is **stigmatization**.

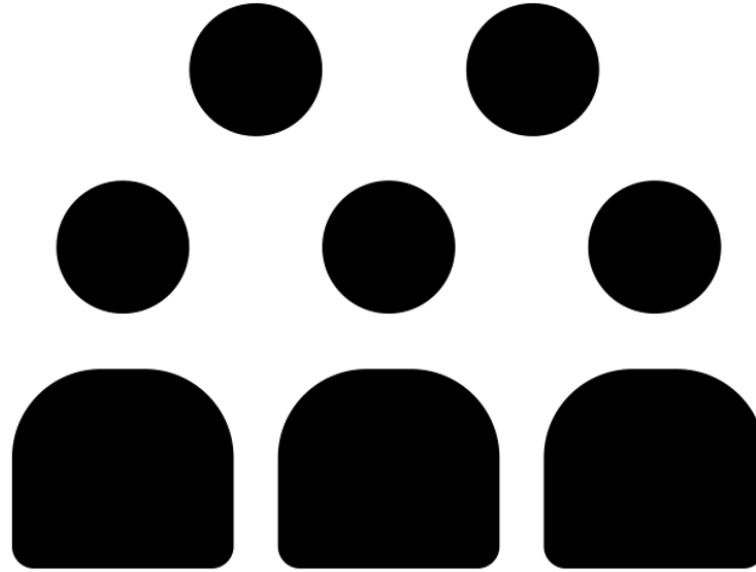
This was mentioned **48** times. Pity and public perception related to cancer were also mentioned frequently.



perception
death others
stigmatization
public cancer
superstition
victimization
pity
perceptions

Peer Support.

202 Respondents confirm association with a patient organization. From these **102** are involved in the day-to-day running of the organization.



Members are actively involved in organizations through the following actions;

Arranging patient meetings

Disseminating disease information

Providing counselling and peer support to other patients.

Financial contributions

76 Respondents are not members of a patient organization.

No time to contribute, geographical location and not having information about the group are shared reasons for not joining.

Life Impact.

Majority of patients note that they live “normal” lives and this contributes to a higher score for quality of life.

Lower scores are attributed mostly to medication side effects.



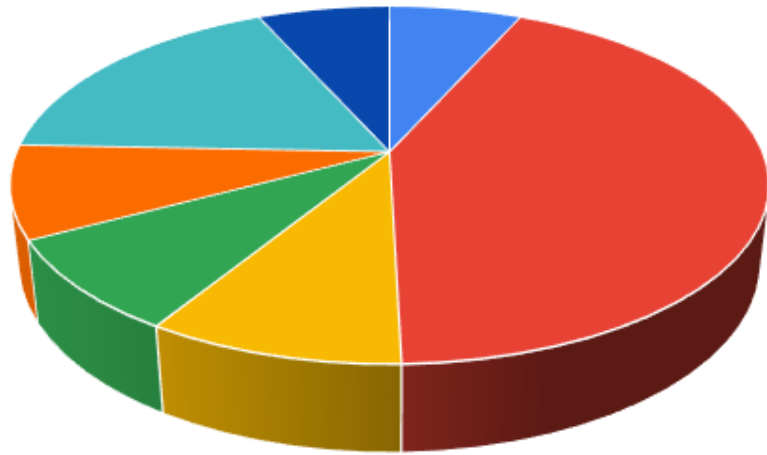
“ In my 17 years of being a CML patient I have been able to hold down a very demanding job, with hardly a day off sick, very little side effects from Glivec. While taking care of my family duties” – 63 year old from Zimbabwe, diagnosed 17 years ago.

“I get fatigued very easily – 47 year old from Ghana, diagnosed 8 years ago.

Patient Needs.

Approximately **26%** of respondents reported that **psychological counselling** would have been valuable at the time of diagnosis followed by **20%** that indicated that **financial assistance** would have been valuable. **10%** Of respondents indicated that **disease information** would have been valuable at the time of diagnosis.

Most asked questions



- Long Term Side Effects
- Side Effects
- Pregnancy and Fertility
- Cause of disease
- Life Expectancy
- Possible Cure
- TFR

The survey allowed for respondents to reflect on questions they have about CML. The questions were grouped by category and **most questions** received are related to **side effect management**. Questions about a cure for CML were noted in high frequency followed by questions related to the cause of disease and CML and fertility/pregnancy. Several respondents also questioned the life expectancy of a CML patient.

Final Words.

The objective of the survey was to capture the Africa and Middle East patient perspective. The vast geographical and cultural diversity of the region will not allow for a general patient profile, or perspective, however in reviewing the data there are common trends across all respondent countries.

Most responded that the cost of confirmation of disease was out of reach and for many unaffordable.

The initial shock and fear at time of diagnoses should also be reviewed in the frame of the reported stigmatization and messages around cancer within these countries and how that attributed to the patient's original anxiety.

Despite the majority of patients stating that they have a good quality of life, the impact of the time and cost of travel to clinics for some does have major influence on their lifestyle.

Uncertainty is noted the cause and transfer of the disease and how to manage the side effects of the treatments. The respondents represent a bigger cohort who might not have the same privilege with regards to access to technology to seek information and it should be considered that the questions and disease impact could even be more complex if the grouping was expanded beyond this survey.

With Thanks.

We sincerely wish to thank each respondent for taking the time to contribute their perspective to our world view of CML.

Thank you to all the patient organization leaders who distributed and collected survey information. We trust this will be of value in your development of strategy and intervention.

We appreciate the contributions from Cathy Scheepers, Region Head for The Max Foundation Africa and Middle East Region and Bahija Goumi, CML Advocates Network Region Liaison.

