

World CML Day 2018

CML QoL Survey: An effort to share the voice of FOM

22nd September is World CML Day and this will be the 11th year of observing this important day in the community of those in whose lives the diagnosis of Chronic Myeloid Leukaemia has and continues to play a great part.

Until a few years ago, CML and its treatment was hardly spoken about. CML was listed as a rare cancer and the prognosis very poor indeed. That, however, is no longer true today.

Glivec, the Magic Bullet, burst upon the firmament of cancer therapy in 2001. Soon after, in 2002, Novartis put in place the first of its kind humanitarian access programme – Glivec International Patient Assistance Programme (GIPAP) with The Max Foundation as the managing partner, holding the hands of thousands of CML patients through their journey. GIPAP changed the face of CML and revolutionised its management.

Hundreds of physicians enrolled thousands of CML patients into this programme; patients who had no recourse to Reimbursement, access to Insurance and could not pay for the drug through private means.

Today there are more than 60 CML Patient Groups in the world and Friends of Max, with a membership that runs into thousands, is the largest of these. When we set up Friends of Max (FOM) as the Support Group Arm of The Max Foundation, I am not sure what we expected but what does exist today surpasses all expectations.

To use the World CML Day motto, “Today, Together”, FOM stands tall as a representative of more than 16000 CML patients. FOM is a testimonial to the strength and fortitude of thousands of CMLers who have redefined what it means to be Living with Cancer.

Amongst the CML family in FOM, are patients who were diagnosed more than 20 years ago and today living full and fulfilling lives. There are young boys and girls who were diagnosed when they were toddlers and who have now finished school and are about to embark on their graduate studies. We have amongst our fold, young adults whose careers were rudely interrupted by CML but who have now managed to rebuild their lives and navigate their career paths via a new normal and get back on to the tracks they were de railed from. Then there are women who only wanted to see their babies get up on their own two feet and today have been able to see them get married and settled . These are people from all socio economic backgrounds, from all walks of life and from the length and breadth of this vast land.

Teachers and students, truck drivers and vegetable vendors, lawyers and policemen, doctors and IT professionals, homemakers and artistes have all shown us what it takes to live with cancer.

These are people who hold in their experiences a fount of knowledge unique to them and to others which if shared can only improve efforts to make sure they continue in their journey with minimum road blocks and continue to achieve maximum mileposts.

The thought of engaging this respondent pool in a survey that could capture some of their experiences was daunting indeed. Spread over this huge land, speaking and understanding different languages, some connected and most not connected via technology, who amongst them we wondered, would most importantly, agree to participate? To agree to share their thoughts and feelings on a most personal, private condition that they may not have even shared with their closest family and friends? However, engage them, we did and we reached out in as many ways as possible - face-to-face in our office and at support group meetings, via phone calls, via our email group, via the WhatsApp groups and via SMS; we got them to take the survey.

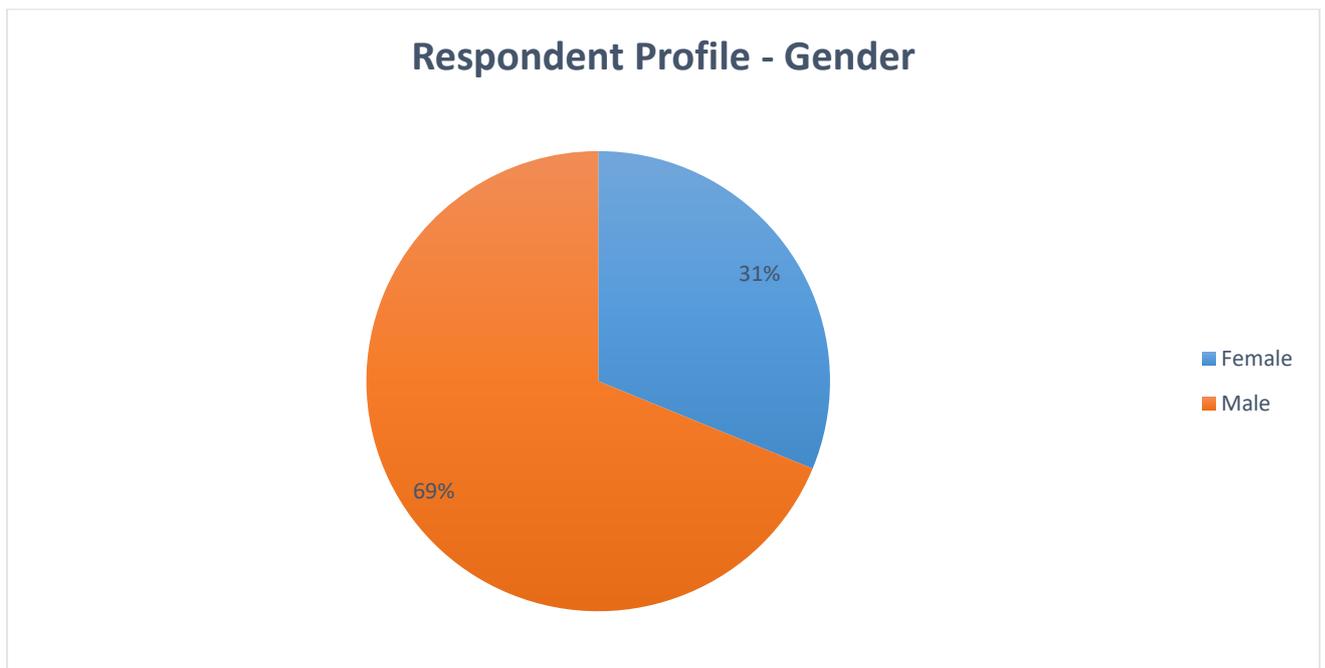
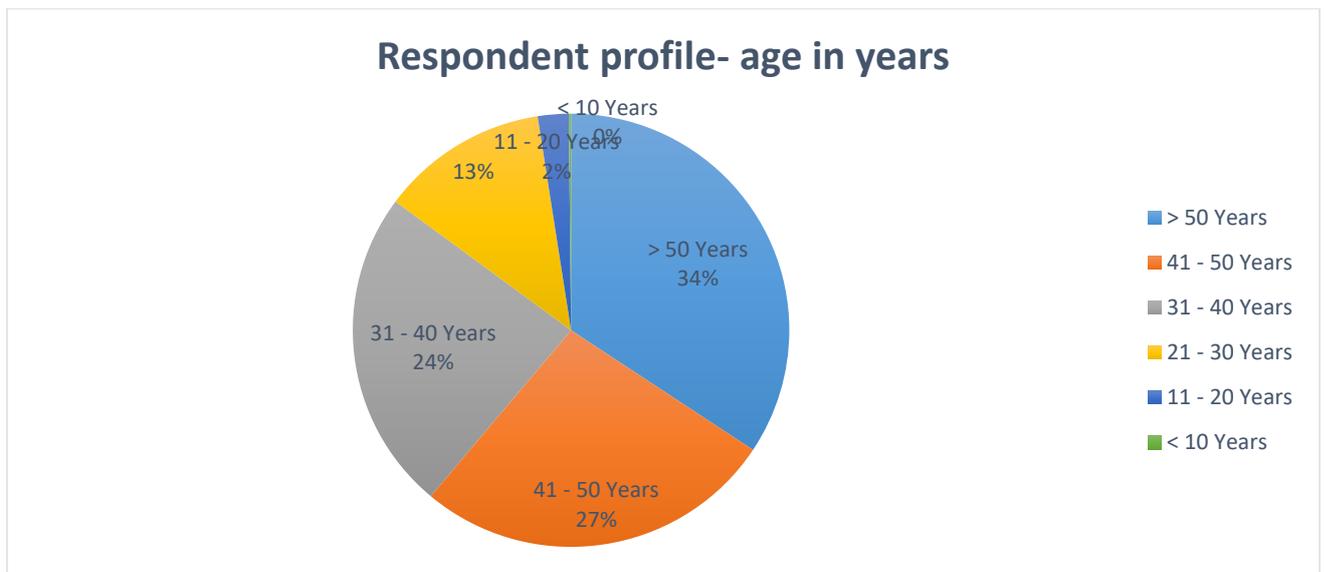
We asked them about their experiences at their workplace, at home, in their schools and colleges; in their villages and towns; we asked whether they faced discrimination, about the role of the stigma of cancer in their day-to-day lives, we asked about factors affecting their quality of life and compliance issues and they responded.

We believe that FOM are a strong presence in the world of CML and have much to share with the global CML family. We envision this CML Survey exercise to be the first step to achieve a better understanding of the patient experience. We recognize the need to place emphasis on raising awareness about one life changing reality – living with chronic myeloid leukaemia (CML) and combat stigma by raising the voices of those facing this cancer.

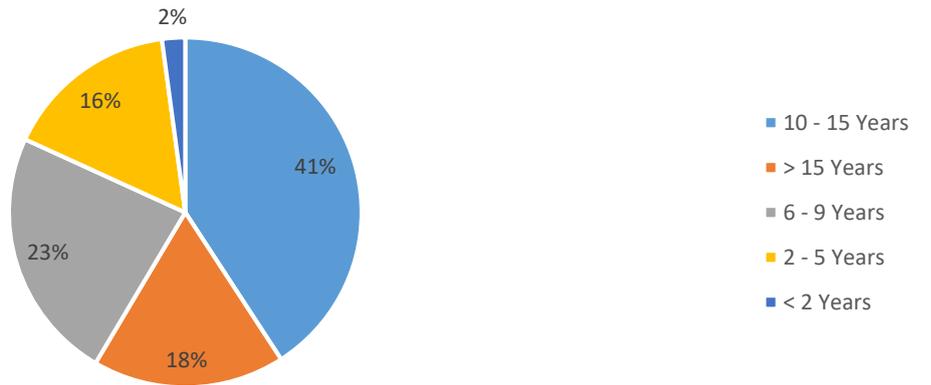
Therefore, it is with the intention of sharing information and wider dissemination of these learnings through the FOM that we have undertaken this survey. This survey is a first step in that direction.

Respondent profile:

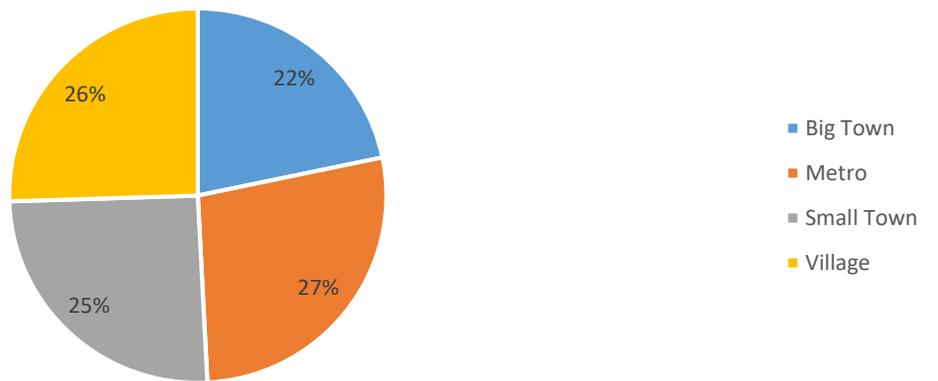
This survey has been taken by a total of 613 persons in the span of approximately a month. It is also important to state that the survey is most definitely not representative of the QoL of our complete patient pool and most certainly not the CML community in the country. However, we believe this is an important focussed, first step to understand the wider experiences of the CML community, not limiting their experience as patients but capturing their broad experience of living with CML.



Respondent Profile - No. of years with CML



Respondent Profile - Location



Respondent Profile - Medication



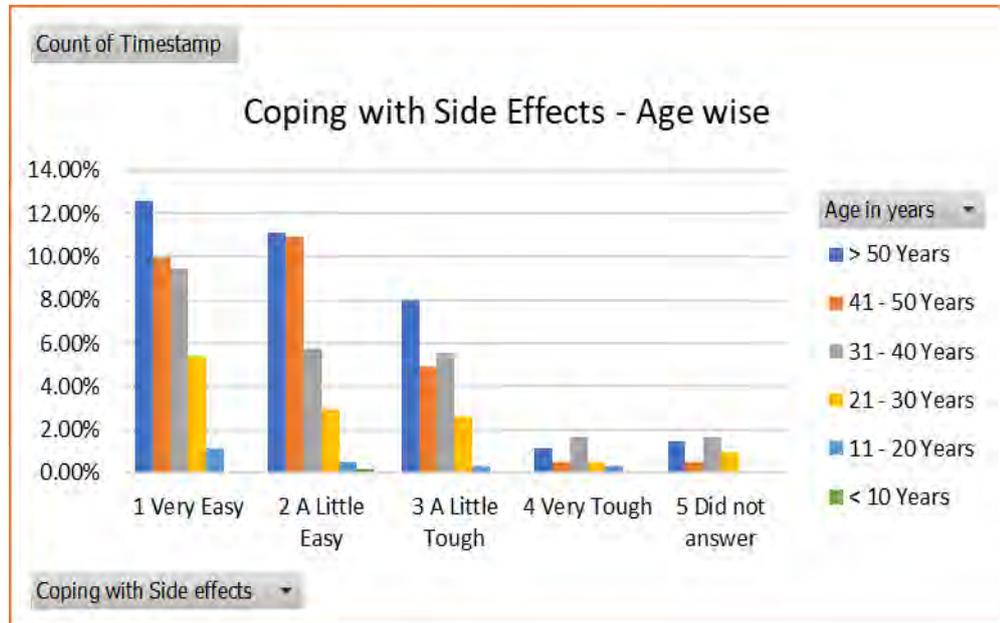
Key areas of analysis

Respondent Profile	Respondent Profile	Age in years
		Gender
		Occupation
		No. of years with CML
		Location:
		Medication
For All	life impact	Coping with Side effects
		Being Compliant
		Being Regular in Follow Up
		Receiving Family Support
For All	Career impact	Completing your studies
		Pursuing your chosen career
		Coping with discrimination at work place
		Effecting a change in your career
		Having the support of your employer
For All	Psychological Impact	Dealing with social stigma
		Coping with pity
		Dealing with fear
		Fighting depression
		Facing one's mortality
		Giving support to peers
Only for answers below 35 years	Young Adults people	Going for higher studies
		Finding a partner
		Planning a family
		Making and keeping friends
Only for answers Above 35 years	Middle / Old	Sharing with children
		Educating Children
		Planning retirement

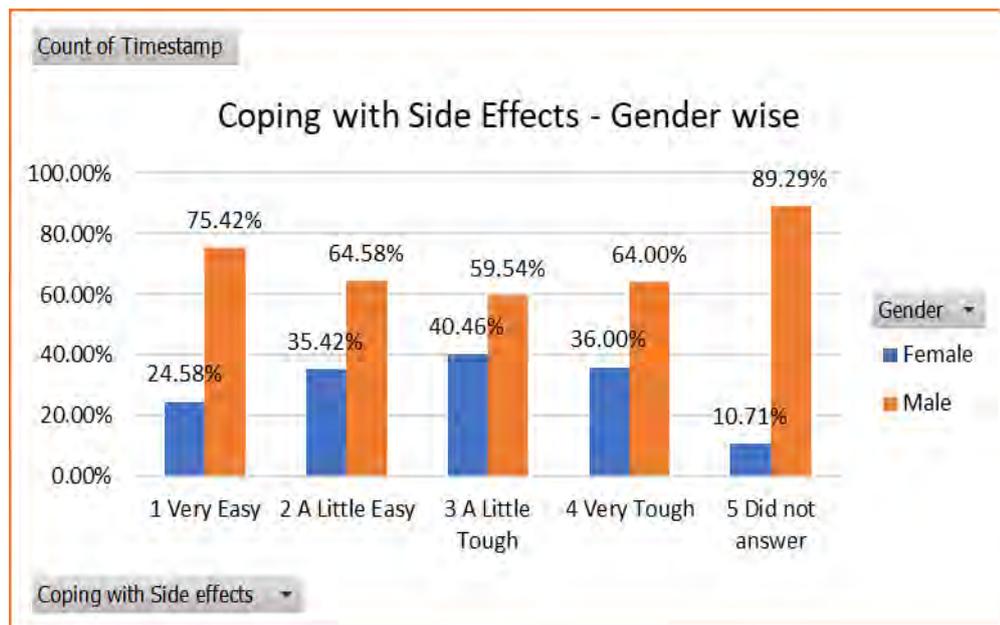
KEY FINDINGS:

SIDE EFFECTS

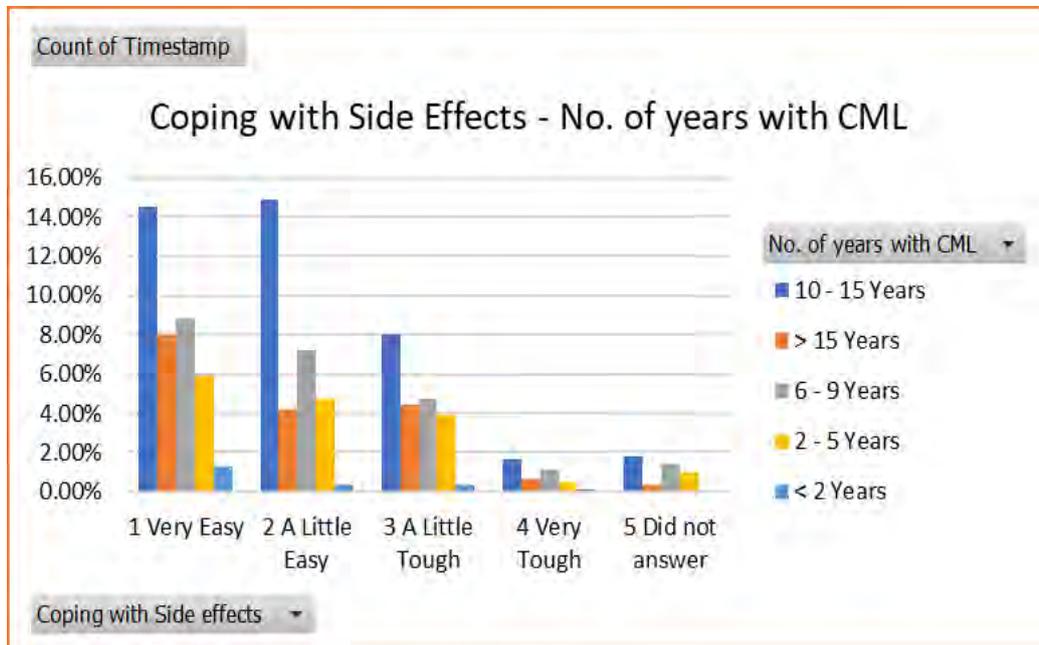
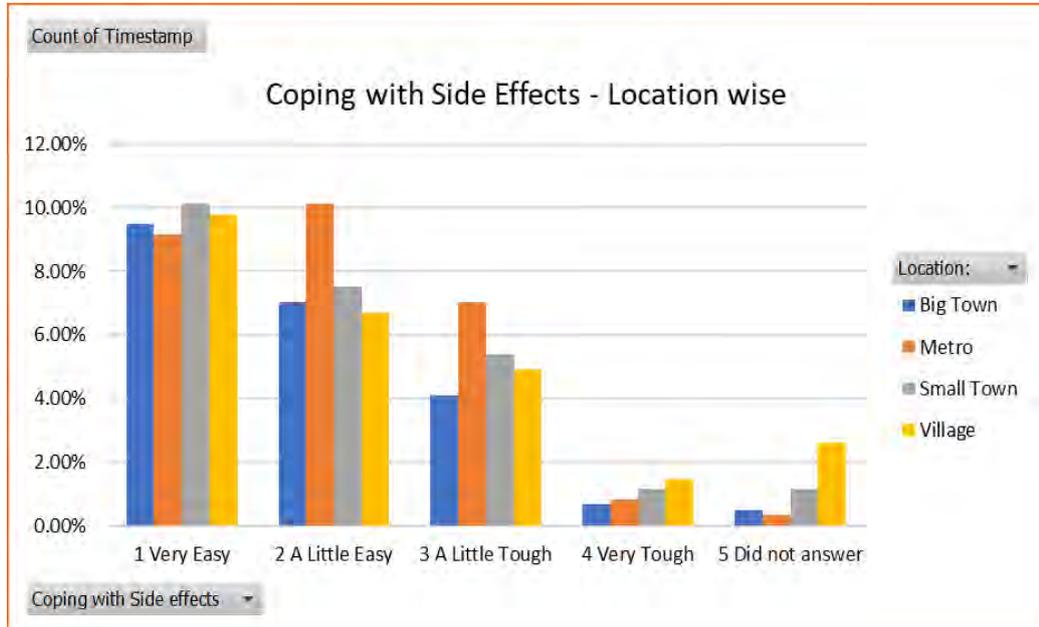
- Age-wise: Of the total respondents, 69% respondents reported that it is very easy/ easy to cope with side effects. Only 4.8% of the respondents reported that it was very tough to cope with the side effects.



- Gender-wise: Of the total respondents, a majority of male respondents reported to finding it more difficult to cope with side effects.

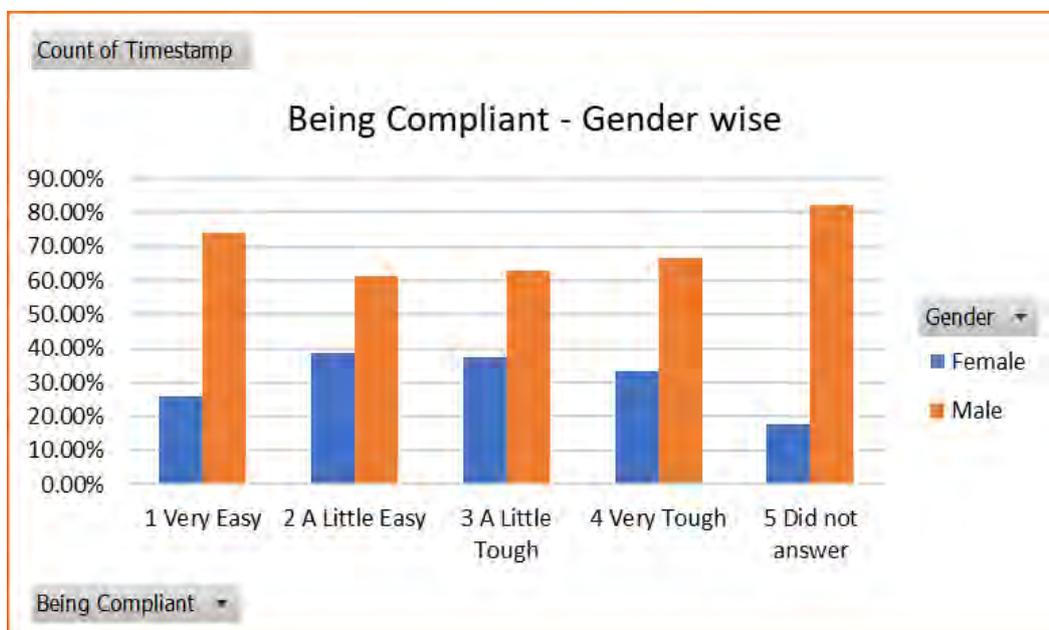


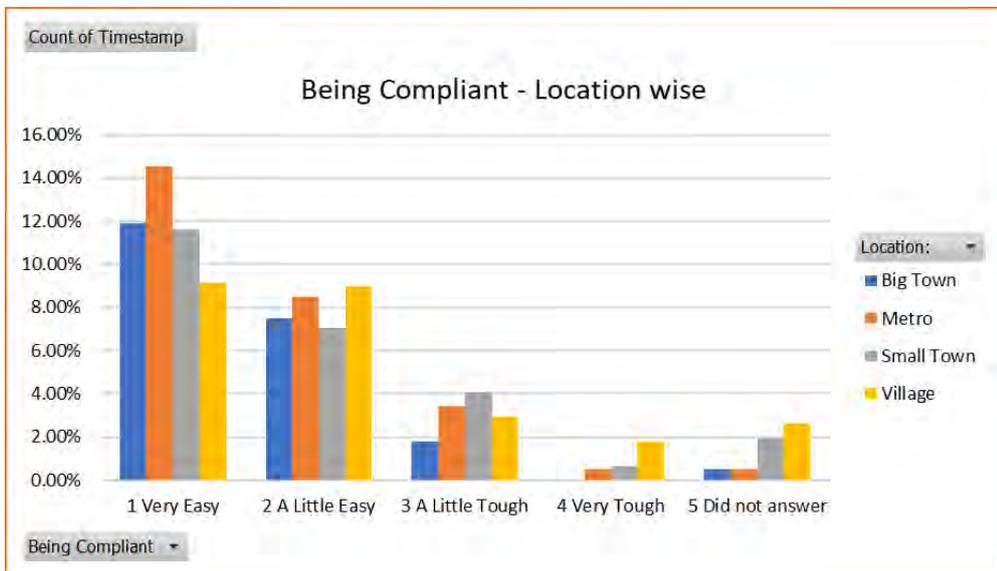
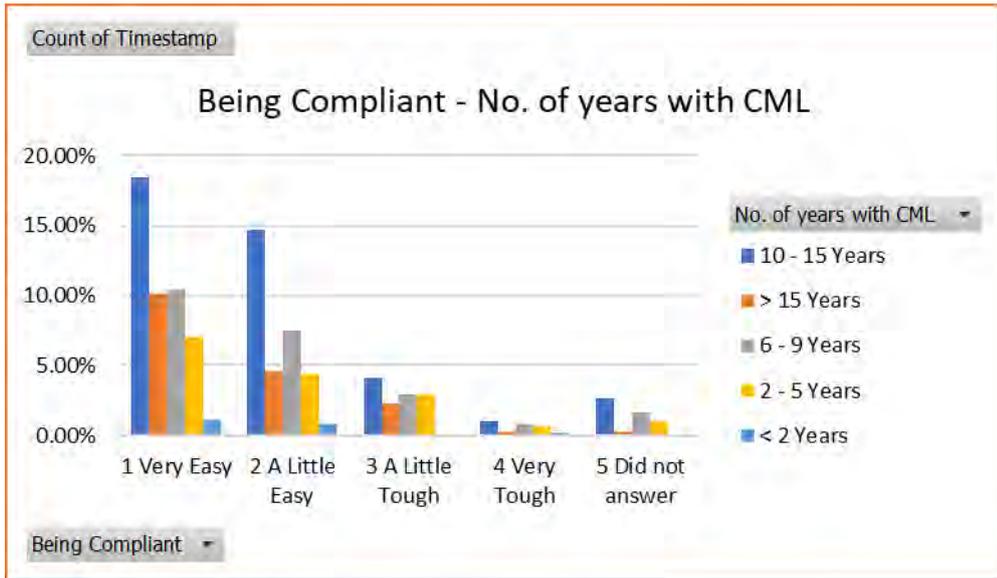
- Location-wise: Across, locations, majority of respondents have reported that is very easy to cope with side effects. The patients' location did not make a discernible difference in their capacity to cope with side effects .i.e no significant difference in the respondents of big towns, Metros v/s those in small towns, villages.



COMPLIANCE

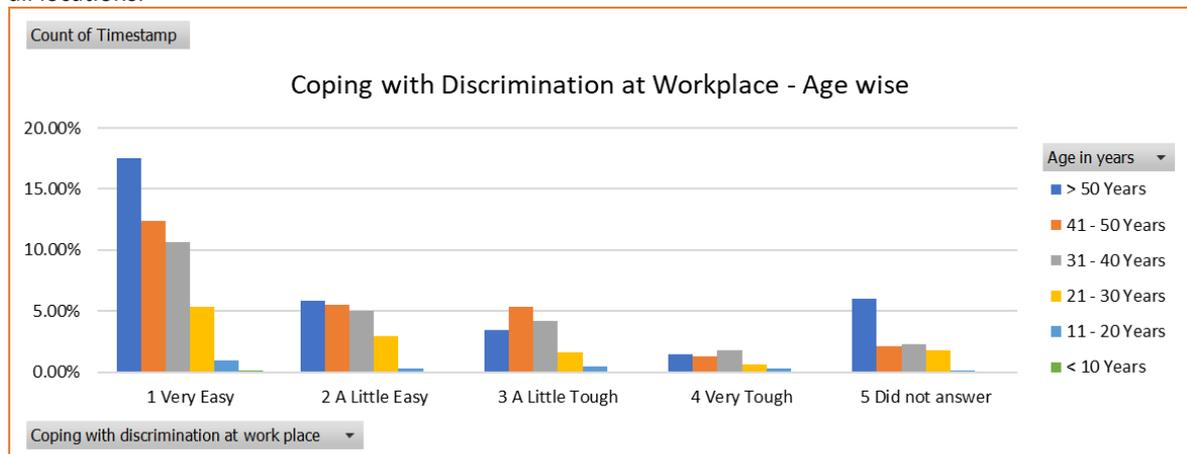
The majority of the respondents have reported that compliance is easy. This is true of respondent groups across Age, Gender, Location and No. of Years on Medication. It is also interesting to note that the patients' location has not adversely affected their compliance. Despite access issues, respondents in small towns and villages have reported to compliance being easy. This can be attributed to repeated sessions / workshops at Patient Support Group Meetings; follow-up calls and patient counselling by the Max team and most certainly, also to the interventions of their treating physicians as well.

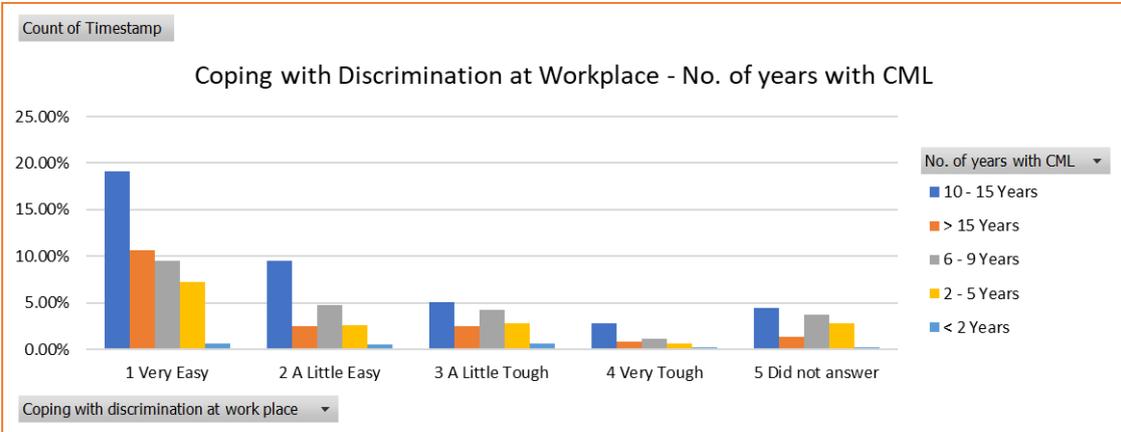
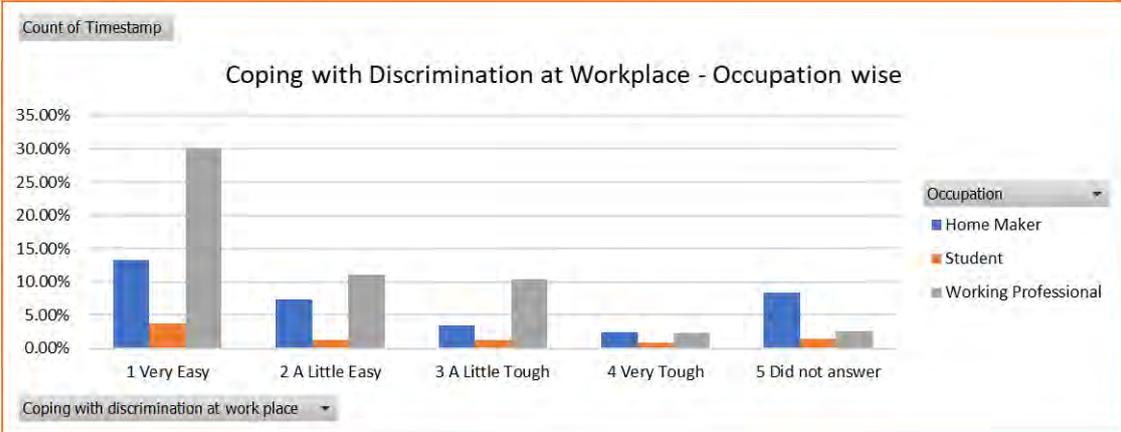
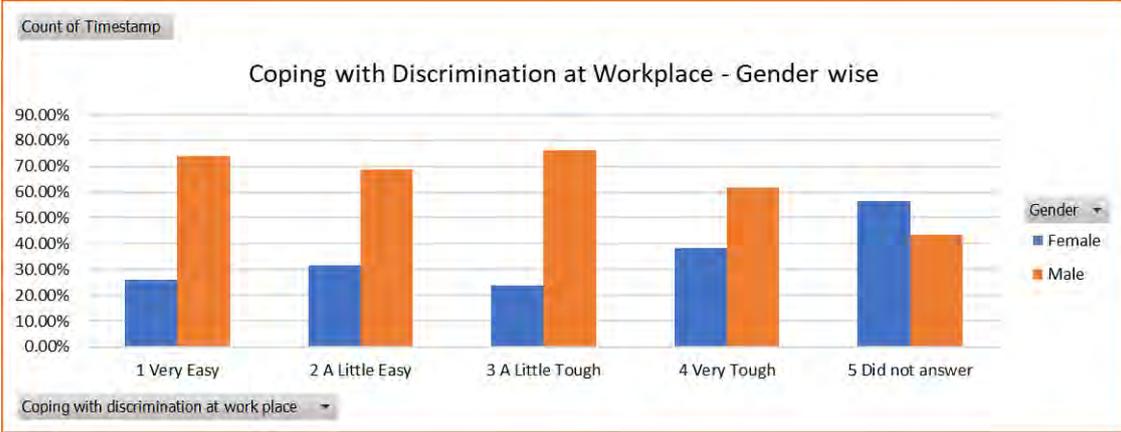




DISCRIMINATION

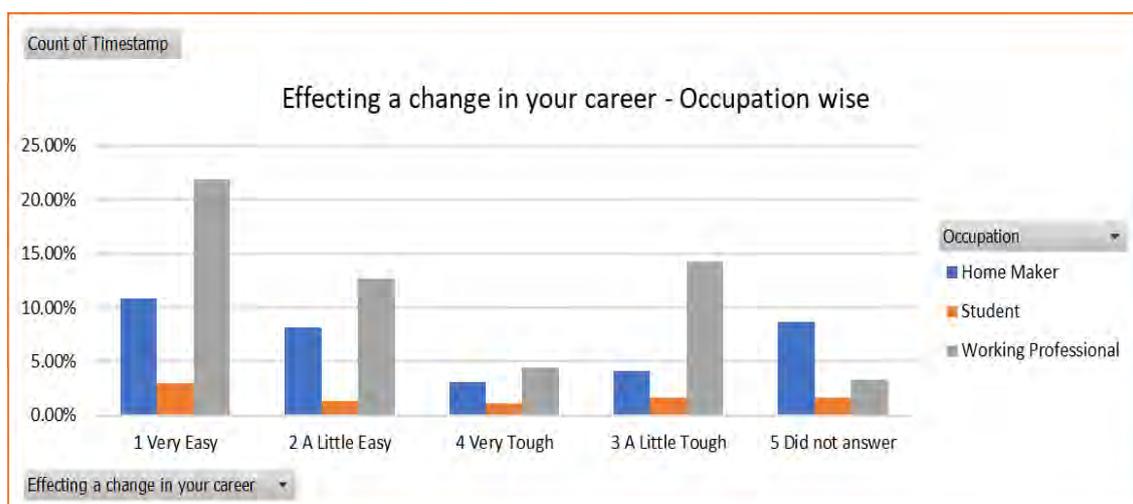
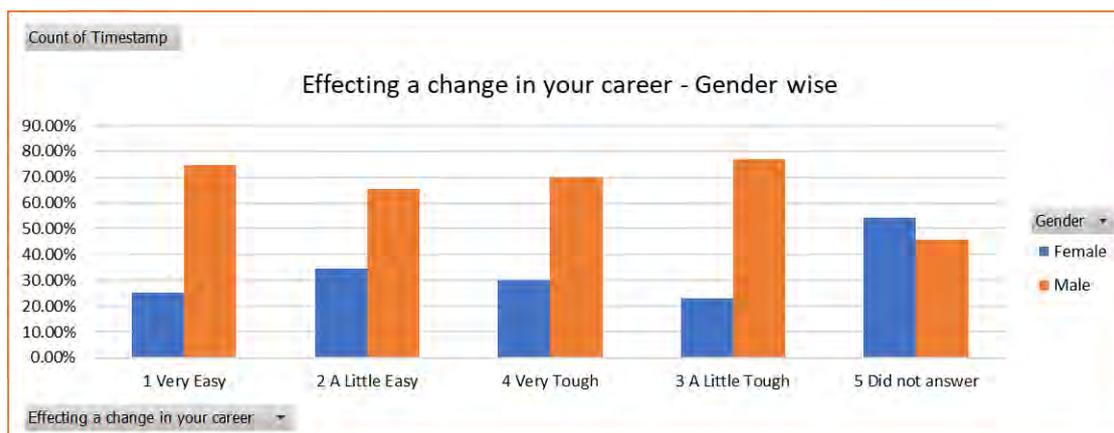
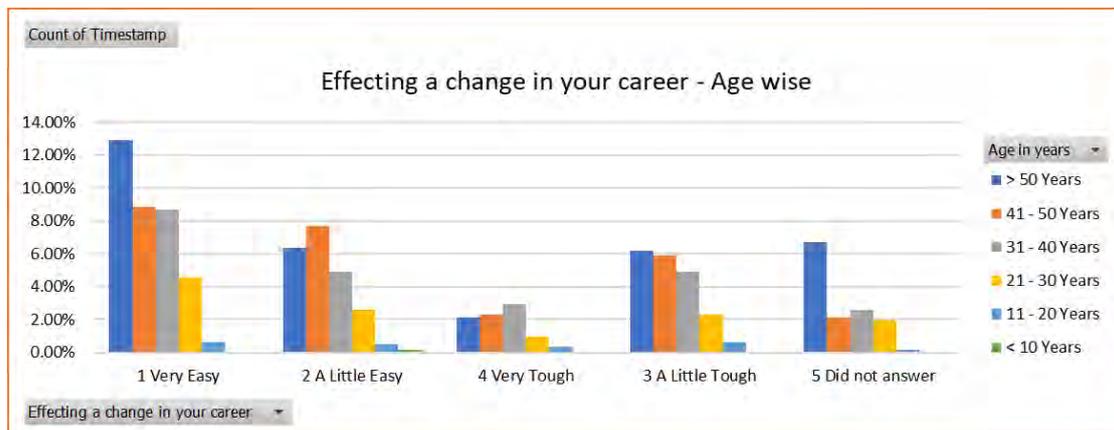
While most patients reported that they did not face any discrimination, amongst those who reported discrimination, it was predominantly reported amongst the male respondents. It is worthwhile to note that during Direct Interviews with some respondents, most patients were extremely grateful to their employers for their support in terms of leave for consultations for periodic monitoring. This is true for patients across all locations.





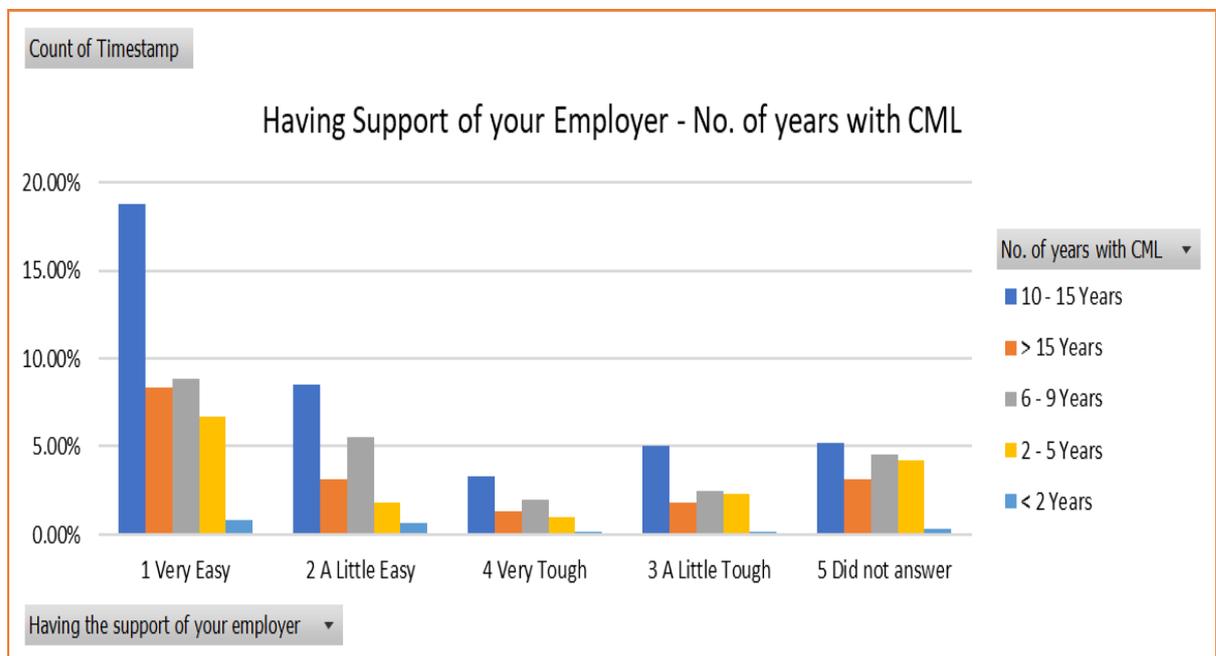
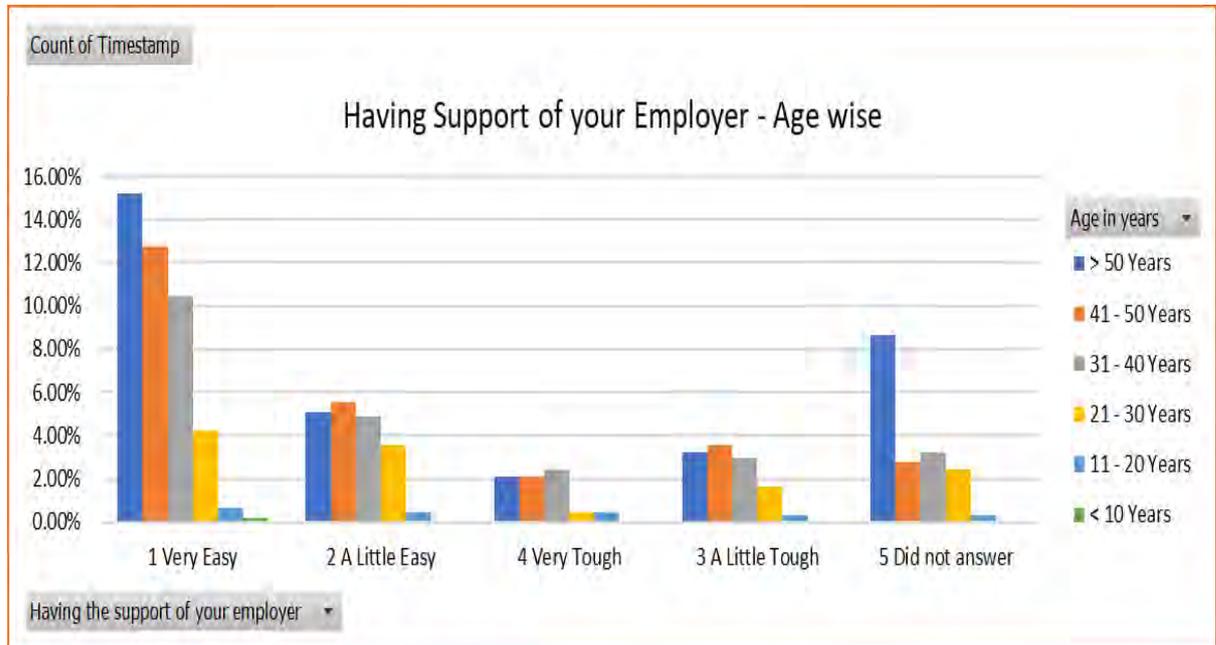
FUTURE PLANNING

Of the total respondents, predominantly the male respondents found it difficult to plan their retirement. This can be attributed to the fact that in India, male members are the predominant breadwinners of the family and the pressure on them to support their family alongside living with CML is quite high. This is reflected in our findings for the data point Educating Children as well. Given the family dynamics in India, retirement typically planned only after buying a house and settling children. Moreover, as per the Survey findings, the burden of financial planning is higher on salaried professionals than on others.



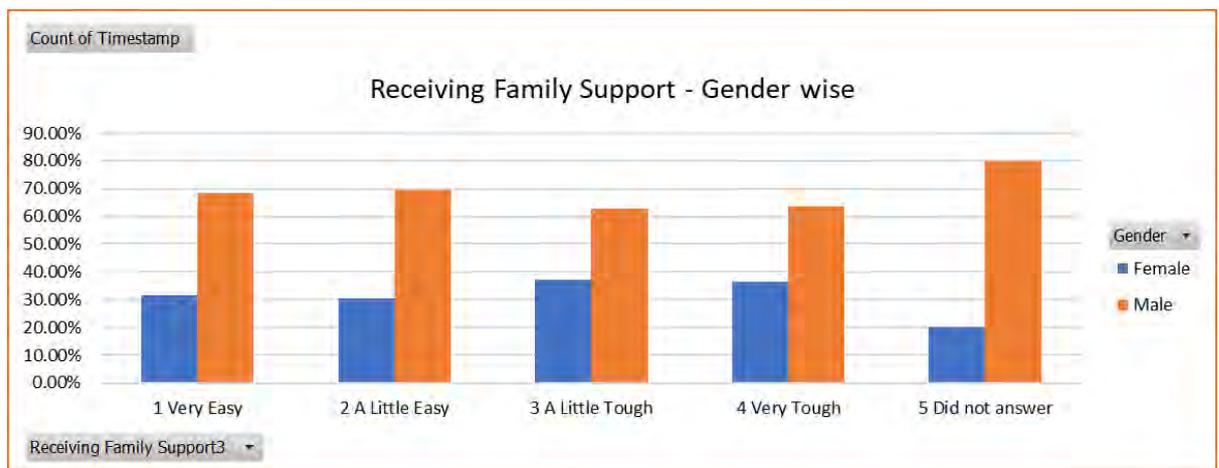
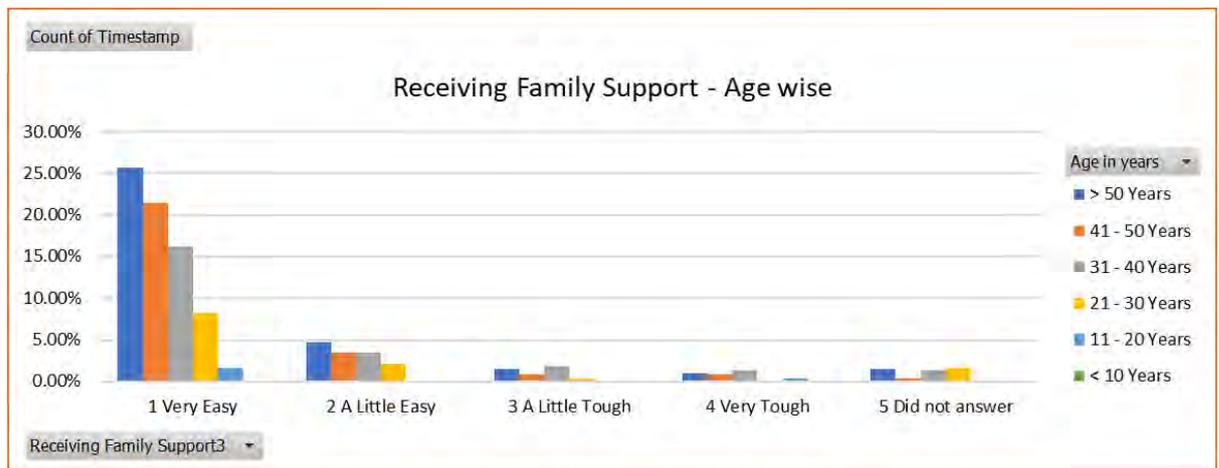
GIVING SUPPORT TO PEERS

75% respondents have reported that it is easy to give support to peers. This can be attributed to the vast outreach of the FOM network through multiple channels like Patient Support Group Meetings, Social Media, WhatsApp groups, Email and other means of communication. This reinforces the work done by the Max Foundation team in India and the FOM volunteers for patient support and advocacy.



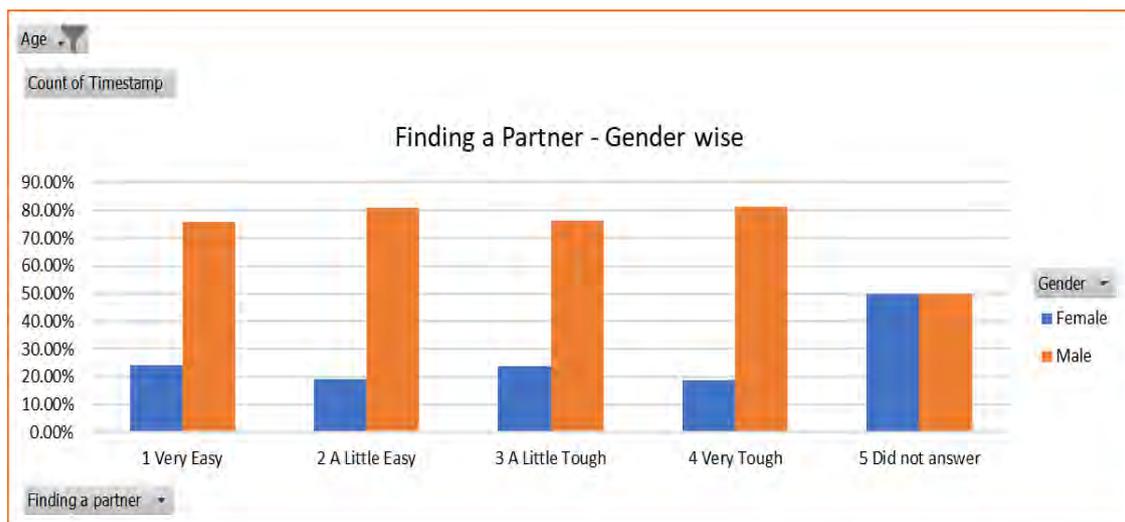
FAMILY SUPPORT & SHARING WITH CHILDREN

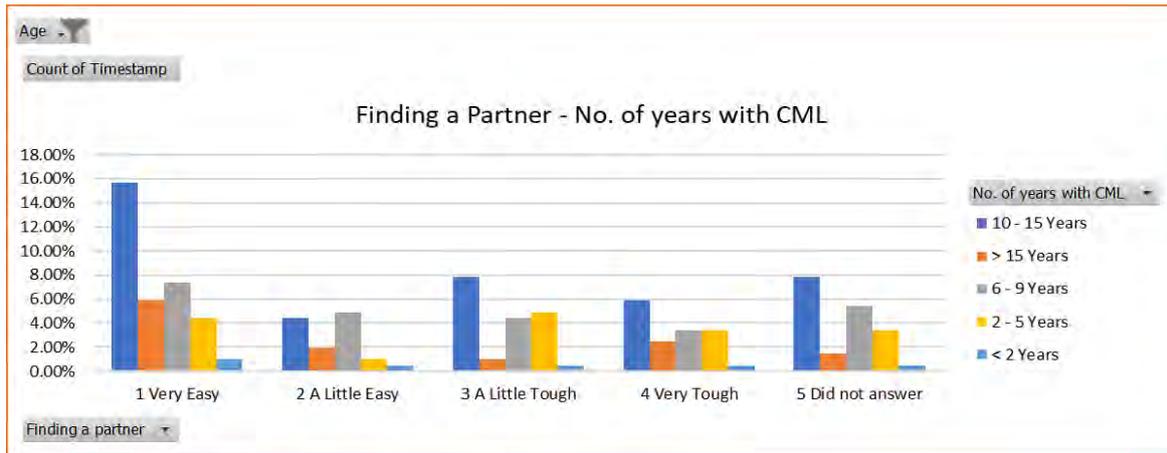
Overall, the majority of the respondents have reported to receive their family support easily. Interestingly though, when looked at closely from the gender perspective, the women have reported to find it tougher than the men have. Given that most respondents have reported to receive family support easily, it is also noteworthy that majority of respondents reported to not having much difficulty in sharing their diagnosis and their changed circumstances with their children- this is true across cities, towns and villages.



FINDING A PARTNER

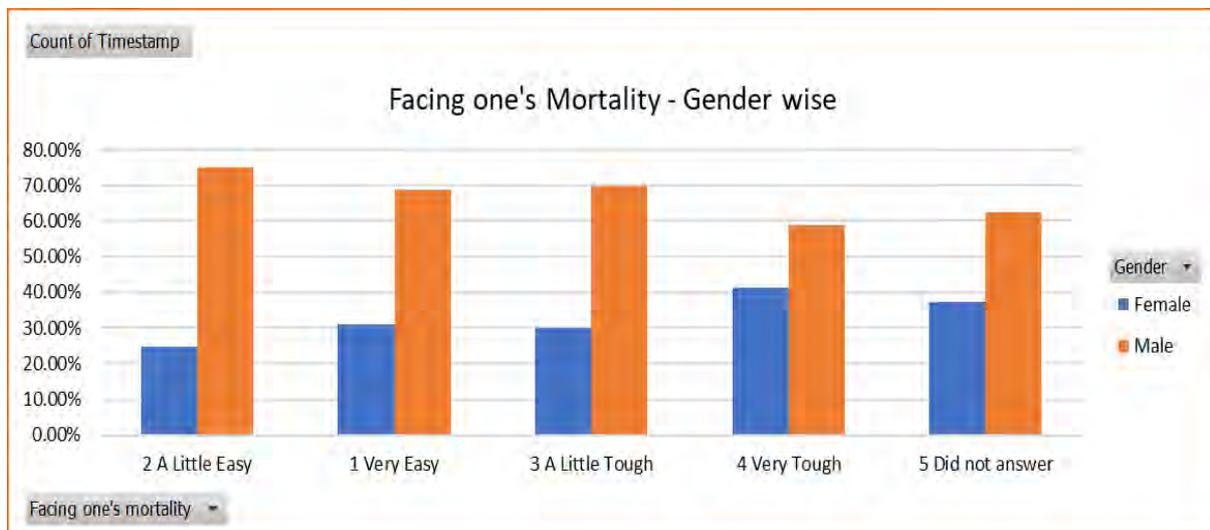
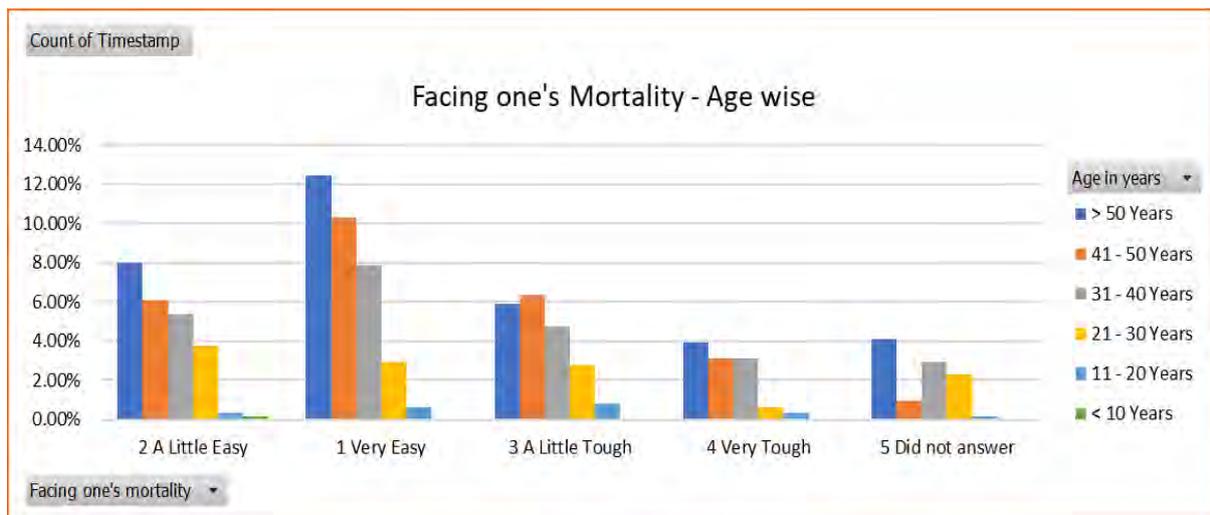
In the age group of 31-40 years, where this would be a relevant concern, 205 respondents have reported that it is tough to find a life partner. Looking at the data gender-wise, men have mostly reported to find it difficult to find a life partner. This is attributable to the perceived dependency on the male members to provide long-term financial security and stability to the family.





FACING ONE'S MORTALITY

As reported by respondents, it can be inferred that the longer the period of living with CML, the easier it is to face their mortality. This can be credited to a multitude of factors that include acceptance, family support, employer support, the role played by the Physician and the advocacy work done by the Max Foundation team in India along with FOM City Chapter Leaders. The FOM CCL's and volunteers are inspiring role models leading by example, supporting and inspiring their CML brethren.



The Survey analysis is primarily Quantitative. However, we have supplemented the Quantitative data with Qualitative analysis as well. This has been done with two open-ended, directed questions that encapsulate the overall Quality of Life of people living with CML; beyond their diagnosis.

They are:

1. If you were to be asked to share one way in which being diagnosed with CML and the path your life took thereafter changed your life , what would that be ?
2. How has being part of The Max Foundation and it's Support Group arm, Friends of Max made a difference in your life since diagnosis?

The responses have given an immensely rich insight into how these patients have struggled with, coped and eventually come to terms with life with a chronic condition.

Living with CML



“When diagnosed with cml it came as a nightmare, but with the support of Max Foundation programme ,wonderful Physicians and Max to team by side as a strong pillars of support, I accepted it . One thing which changed was that I stopped taking extra tension of work and tried to come out of rat race. It became very clear that family is the only thing which stands by your side at any such real tough times.”

-Apar Singh Arora



 **The Max Foundation**
www.themaxfoundation.org

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Friends of Max
www.friendsofmax.info

Living with CML



“It made me more introspective. Being part of The Max Foundation & Friends of Max was akin to being provided with the shelter of a large friendly umbrella in the midst of pouring rain ! “

- Dr. Jude



 **The Max Foundation**
www.themaxfoundation.org

**Quality of Life Survey
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Friends of Max
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Living with CML



“At diagnosis, the future looked bleak and death seemed imminent, but things improved once Imatinib was started. With a little change in career path, the Quality of Life has been excellent.

It has given me an understanding of how others view their disease and scope to reach out and reassure them that with current treatment the condition is no different than diabetes or asthma.”

- Dr. Raghu Krishnaswamy



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Living with CML



“CML has given me and my family a better perception and understanding towards life. The Max Foundation and Friends of Max has been the biggest support ever since my diagnosis and has literally given me a second chance to lead a better life.”

-Parveen Bashir



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Living with CML



“The most important thing is to regularly take medication as prescribed by the Physician and confidently lead life without fear and do good be good.”

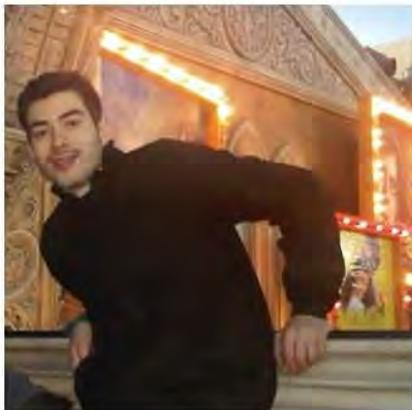
-Lakmana Rao



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Living with CML



“Being diagnosed with CML was a major setback that came in my life. The initial phase was the toughest and changed my perspective towards life and made me stronger to deal with the worst of situations at hand. “

- Manhar Kocchar



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Living with CML



“Living well with realisation and benefiting from a huge network of friends, the important sessions and programs held for educating patients alongwith interaction from Doctors who are at the top of their areas of interest in oncology and cancer care.

It has helped me to ride over the initial shock and look at life anew with hope and joy. It has helped me coexist with the condition without stopping myself from progressing in life and career as any non-patient. It has given me the confidence to be myself and march forward. It has given me my Viji Amma, our larger than life caregiver and bear hug therapist :-)”

-MP



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Living with CML



“Even though it was a little difficult personally and on family to cope up initially, CML has made a huge impact on the way I look at the world or do things in life. It has been life changing in the sense that I'm much more determined and passionate in moving further and pretty much in doing everything.

It has made all the difference. Max foundation and it's support group arm, Friends of Max makes life much easier in every sense, starting from the support with medicines to understanding life with CML in a much better way by bringing together patients who can share their stories and support each other. This is the reason that I'm able to lead a normal life because of Max foundation.”

-Priyanka Bopanna



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Living with CML



“It made me want to live life the way I want to, and not as how others want me to.

I'm lucky to have discovered a new family!”

-Nirmesh Prakash



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Living with CML

“My life hasn't changed. My attitude towards life and other people has changed. I am have become more compassionate. I have touched more lives positively after being diagnosed with CML ...that's the kind of feedback I have received from people of all age groups dealing with CML and other life situations.

CML has been a blessing for me.

The Max foundation has laid the foundation for my life . It has given me a platform to share and care , raise my concerns, get to know other CML survivors and their story. Every individual of this group is compassionate to the core and that's what everyone needs. Glivec has been my life saver and the support group has made me look beyond CML. “

-Ratika, Hyderabad



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Living with CML



“Max Foundation is the most important part in my life . Max Foundation returned my life back to me. It supported me mentally and physically. It gives me strength to overcome the obstacles in my life. Friends of max gives me much more information about medicine and about CML and it also gives great support in my life. I am thankful to Friends of Max and Max Foundation to be a great part of my life. “

THANKS

-Sharafudheen



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Living with CML



“Since the diagnosis of CML, I have learnt to value life. I have come across people who have stretched their hands to help patients without any personal gain.”

- Stuti Koner



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Living with CML



"Initially it was all very difficult to handle but when I started attending Friends of Max patient meeting. I accepted the facts and my life normalized. Now I am fine with the things and working as normal person."

- Sahishikant Jakhade



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Living with CML



"From being given 3-5 years of survival, to making it this far (15 yrs) ...feeling very blessed."

-Sailaja Kosuri



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