Living with CLL

Results from the quality of life survey among CLLSA members

September 2014
Overview

• A survey was conducted by CLLSA to better understand the impact CLL has on quality of life (QoL)
• The survey consisted of four open questions
  1. How long have you been diagnosed with CLL?
  2. If you are still in ‘watch and wait’ what have been the key issue/s that have most affected your quality of life?
  3. If you have had treatment, please indicate the nature of the treatment
  4. Post-treatment, what have been the issues that have most affected your quality of life?
• A quantitative analysis has been conducted to identify trends in the survey results
Infections was the most frequently reported physical issue for those post treatment.

*‘Watch and wait’ is a term often used to describe both the period of time before treatment initiation, as well as after a course of treatment has ceased. For the purpose of analysis, watch and wait only refers to those who have not yet taken treatment. **Post-treatment statistics also include those who are currently on treatment.

84% of all respondents reported a negative impact of CLL on their quality of life.

Anxiety was the most frequently reported emotional issue.

Fatigue was the most frequently reported physical issue for those in watch and wait.

1.5 to 288 months is the length of time respondents had been living with CLL.

282 CLLSA members completed survey.

Respondents by patient type:
- 39% Watch and wait*
- 61% Post-treatment**
Executive summary

Watch and wait

- 173 people in watch and wait
- 86% respondents in watch and wait reported a negative impact of CLL on their quality of life

Anxiety was the most frequently reported emotional issue with 85% of respondents reporting this issue.

Fatigue was the most frequently reported physical issue with 72% of respondents reporting this issue. Post-treatment this decreased to 47%.

Post treatment

- 109 people post-treatment
- 81% respondents post-treatment reported a negative impact of CLL on their quality of life

Anxiety issues decreased post treatment with 51% reporting these issues.

Fatigue decreased post treatment with 47% of respondents reporting this issue.

Infection & immune system issues were the most reported physical issues with 49% of post-treatment respondents reporting these issues compared to 36% of the watch and wait patients.
Who completed the survey

No. of respondents who are in pre treatment watch and wait vs. post-treatment

No. of years respondents have been living with CLL

**Insights**
- Of the 282 respondents, 61% had not yet taken any treatment for their CLL
- The length of time respondents had been living with CLL ranged from 1.5 months to 288 months (24 years)
Reported QoL impact for pre-treatment watch and wait patients

• The following slides are an analysis of responses to question 2: if you are still in watch and wait what have been the key issues that have most affected your quality of life?
Insights

- 86% respondents still in watch and wait reported a QoL impact due to CLL
- This varied from 78% to 90% depending on the length of time the respondent had been living with CLL with the highest incidence reported at 3-5 yrs (78% 0-2 yrs, 90%, 3-5 yrs 88% 6-8 yrs, 87% 9+ yrs)
Insights

• Overall, the incidence of physical QoL issues was highest among respondents (72%) followed by emotional quality of life issues, which affected nearly half of respondents (46%)
• Incidence of physical QoL issues increased with length of time living with CLL from 66% at 0-2 yrs to 80% at 9+ yrs
• Incidence of emotional QoL issues was highest among the 0-2 yrs group (52%), this was also high among the 9+ yrs group (50%)
**Breakdown of the emotional wellbeing issues the 68 respondents have experienced during watch and wait**

<table>
<thead>
<tr>
<th>Issue</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frustration</td>
<td>1</td>
</tr>
<tr>
<td>Helplessness</td>
<td>2</td>
</tr>
<tr>
<td>Depression/feeling down</td>
<td>8</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>4</td>
</tr>
<tr>
<td>Stress</td>
<td>7</td>
</tr>
<tr>
<td>Concern over infection and when to see a doctor</td>
<td>5</td>
</tr>
<tr>
<td>Anxiety/concern/uncertainty</td>
<td>58</td>
</tr>
</tbody>
</table>

**Insights**

- 85% of respondents stated experiencing anxiety, concern or uncertainty about living with CLL.
- Anecdotal responses suggest that the same anxiety is felt regardless of the period of time living with CLL.
Breakdown of the security issues the 16 respondents have experienced during watch and wait

- Access to new treatment on the NHS: 1
- Travel insurance/insurance: 5
- Planning for the future: 9
- Money: 4
- Work: 6

Insights
- Planning for the future was the most frequently reported security issue (56%) followed by work related issues (38%)
- 31% of respondents reported an increase in travel insurance/insurance costs
Breakdown of the physical issues the 107 respondents have experienced during watch and wait

Insights

- The incidence of fatigue and tiredness was highest among respondents (72%) followed by immune problems and infections (36%)
Insights

• The incidence of feelings of isolation was highest among respondents (53%) followed by lack of support (41%) and impact on family relationships (41%)

• 35% respondents found disclosure or communicating about CLL an issue

Breakdown of the relationship issues the 17 respondents have experienced during watch and wait

- Isolation: 9
- Disclosure/communication: 6
- Support: 7
- Friends: 2
- Family: 7
- Other: 2

Other =
• Doctors not understanding how we feel
• Others understanding or listening

Feel isolated. Coming to terms with diagnosis. Managing the seriousness of the diagnosis. Knowing when to seek GP advice such as with heavy cold due to concerns about infection. Feel something could be done to help newly diagnosed patients

0-2 yrs

Whom to tell, anxiety, feelings of helplessness, being told you have a potentially life threatening illness, which is ‘nothing to worry about’ and being told to ‘go away and we’ll see if anything happens’

6-8 yrs
Insights

- The incidence of impact on social life was highest among respondents (55%) followed by an impact on travel and holidays (36%)
Reported QoL impact for post-treatment patients

• The following slides are an analysis of responses to questions 3: if you have had treatment, please indicate the nature of the treatment; and 4: post-treatment, what has been the issue/s that have most affected your quality of life?
Breakdown of the treatments received by the 109 respondents in the ‘post-treatment’ category

FCR (together) 45
FCRM 4
Fludarabine 11
Alkylating Agents (Cyclophosphamide & Chlorambucil) 19
R-CHOP 7
Rituximab 14
Bendamustine 11
Chemotherapy non specified 23
Steriods 8
Clinical trial 17
Blood transfusion 4
Other 21

Clinical trials
• Admire (x1)
• Arctic (x4)
• Idelalisib (x1)
• Resonate/2 (x2)
• Rialto (x4)
• Not specified (x5)

Insights
• Combination treatment (Fludarabine, Cyclophosphamide, Rituximab) was taken by the highest number of respondents (49%) followed by a non-specified chemotherapy (21%)
Insights

- 81% respondents post-treatment reported a QoL impact due to CLL
- This varied from 76% to 87% depending on the length of time the respondent had been living with CLL with the highest incidence reported at 0-2 years (87% 0-2 yrs, 79%, 3-5 yrs, 76% 6-8yrs, 83% 9+ yrs)
Insights

- Overall, the incidence of physical QoL issues was highest among respondents (86%) followed by emotional quality of life issues (16%)
- Incidence of physical QoL issues increased with length of time living with CLL from 77% at 0-2 yrs to 97% at 9+ yrs
- Incidence of emotional QoL issues was highest among the 6-8 yrs group (32%), this was also high among the 0-2 yrs group (23%)
Insights

- 57% of respondents reported experiencing anxiety, concern or uncertainty about living with CLL
- No respondents felt stressed or concerned about when to see a doctor regarding infections
Breakdown of the security impact the 8 respondents have experienced post-treatment

- Travel insurance: 1
- Planning for the future: 1
- Money: 1
- Work: 6

Insights
- The incidence of work related issues was highest (86%) among respondents
**Insights**

- The incidence of immune problems and infections was highest among respondents (49%) followed by fatigue and tiredness (47%).
General fatigue, less active with family and friends. I have to select specific events to do and then hope that I have the energy to do them. 
*Alkylating Agents patient, 6-8 yrs*

Relative isolation due to avoiding infection in crowds, difficulty in making medium term commitments due to unpredictability of health and less confidence in undertaking some activities. 
*Rituximab and Bendamustine patient, 6-8 yrs*

**Insights**

- The incidence of feelings of isolation and family relationships were highest among respondents (50%)
Insights

- The incidence of impact on social life was highest among respondents (67%) followed by an impact on travel and holidays (50%).

Breakdown of the fun impact the 6 respondents have experienced post-treatment

- Feeling restricted: 1
- Holidays/travel: 3
- Hobbies: 1
- Social life: 4

Adverse effect to treatment. Unable to travel abroad and book holidays in advance due to pending treatment and after effects.

Alkylating Agents Rituximab and Bendamustine patient, 9+ yrs

Low platelet/neutrophil/Hb counts. Advised to eat cooked foods only and no eating out in restaurants, no social activities involving crowds, life is very restricted.

R-CHOP, Rituximab and Bendamustine patient, 9+ yrs
Conclusions and recommendations

• Overall, incidence of **physical QoL** issues were highest across both groups (72% watch and wait and 86% post-treatment)
  • This suggests that education on the disease progression of CLL should be of equal importance for both watch and wait and post-treatment patients
    • For **watch and wait** patients, education on symptom progression and monitoring will be important
    • For **post-treatment** patients, education on monitoring side effects will be important
• Fatigue and tiredness was a particular issue for 77% of the watch and wait patients, suggesting it would be beneficial to ensure advice is available on how to manage this, as well as prioritising treatment innovation in this area
• Infections and immune system issues increased after treatment, with 49% of post-treatment respondents reporting issues compared to 36% of the watch and wait patients. This suggests that greater researcher into treatments for those who have already incurred immune system problems is needed for CLL patients
• Anecdotal responses suggest that watch and wait patients would benefit from practical guidance and advice about when to visit a doctor concerning an infection – as well as better GP education around CLL management
Conclusions and recommendations...cont’d

• Incidence of emotional QoL issues was high among the watch and wait group (85%) but dropped to 57% in the post-treatment group
  • This suggests that patients need much more emotional support to deal with living with CLL than those who have been on treatment. 85% of watch and wait respondents experienced feeling of anxiety and concern about living with CLL and more than a third of respondents experiencing the emotional impact of CLL expressed issues around disclosure and communication about their condition
• Incidence of security, relationships and fun QoL issues were low among both groups
  • This could be due to the survey design (which allowed free text responses only i.e. there were no pre-defined lists/triggers to consider issues in these areas). Security, relationships and fun could also be perceived to be ‘secondary’ QoL issues (with the physical or emotional issues being primary issues)

Insights
• Taken together, the incidence of QoL issues suggest that patients would benefit from being treated in a holistic manner, in which their care is managed by a multidisciplinary team. This would ensure that physical issues, such as infections and emotional issues, such as anxiety, were managed by the most suitable healthcare professional
• This would ensure that patients receive the best possible treatment, management and care for their health needs
Future surveys

• It is recommended that future surveys should further explore the physical and emotional impact of living with CLL, particularly what support and advice people living with CLL have received. A good understanding of what support to offer patients and at what stage of the disease may help towards addressing the anxiety and concern watch and wait patients experience whilst living with CLL, as well as offering guidance and support to those who need practical advice on dealing with the side-effects of the disease or treatments currently available.

• It would be valuable to further explore the impact on security, relationships and fun by including pre-defined lists in the survey.

• It would be valuable to capture the age of respondents to explore any age related CLL issues.

• The current survey does not take into account the type of support received from healthcare professional to combat QoL issues, therefore it would be valuable to capture this information in a future survey.