

Quality of life issues for people living with CLL Survey of 282 CLLSA members

Executive summary

The Chronic Lymphocytic Leukaemia Support Association (CLLSA) has long been aware of the quality of life issues experienced by those living with chronic lymphocytic leukaemia (CLL). However, there has been limited data collection to explore the true extent of its impact. In order to find out more about the quality of life issues for those living with CLL, data were collected from 282 CLLSA members living with CLL who answered an online survey between January and December 2013. Respondents were asked to answer four open questions, which included the amount of time they have been living with CLL, the impact CLL has had on their quality of life before they initiated treatment (also referred to as the 'watch and wait' period), the treatment they have received (if any at all) and the impact CLL has had on their quality of life post-treatment (if relevant). Results from this survey suggests that for both 'watch and wait' patients, as well as those who have received treatment, physical problems were the most reported quality of life issue, followed by emotional issues. Specifically, for those in the 'watch and wait' stage of their CLL, fatigue and tiredness were the most reported issues along with anxiety for the future. In the post-treatment group, infections and immune system issues were most reported. In order to gain a deeper understanding of quality of life issues among those with CLL, a follow-up survey is recommended.

Introduction

Quality of life is an important measure of disease progression and impact. The World Health Organisation Quality of Life (WHOQOL, 1997) measure suggests that quality of life can be broken down into 6 areas: physical health, emotional/psychological wellbeing, independence (including financial security and work capacity), relationships, environmental issues (including leisure activities) and personal beliefs. Living with a condition such as CLL can have a serious impact on these areas; therefore the clinical research community felt that more research was needed into how CLL affects quality of life. The CLLSA reached out to its members to participate in a survey to explore quality of life issues in 'watch and wait' patients and those who have received treatment.

Method

Data were collected from 282 CLLSA members who answered an online survey between January and December 2013 around quality of life issues in CLL. Respondents were asked four questions and had the opportunity to respond in free text, the questions were:

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?

In order to quantitatively analyse the feedback from the participants, answers were categorised depending on whether respondents reported being in 'watch and wait' or whether they had received treatment. Furthermore, quality of life issues were broken down into five areas for further analysis: physical issues, emotional issues, security issues, fun and social life issues and relationship issues. Beyond that, the responses were broken down into specific impacts. For example, within physical issues, fatigue, infections, night sweats etc were logged. The breakdowns were based on keywords within the answer.

Results

A total of 282 CLLSA members completed the survey and, of these respondents, 173 people indicated that they were in 'watch and wait' and 109 respondents indicated that they had received treatment.

The length of time respondents reported living with CLL ranged from 1.5 months to 288 months (24 years). Table 1 (below), shows that this varied slightly between patients in 'watch and wait' and patients who had received treatment. As expected, those who had received treatment had been living with CLL for a slightly longer amount of time on average.

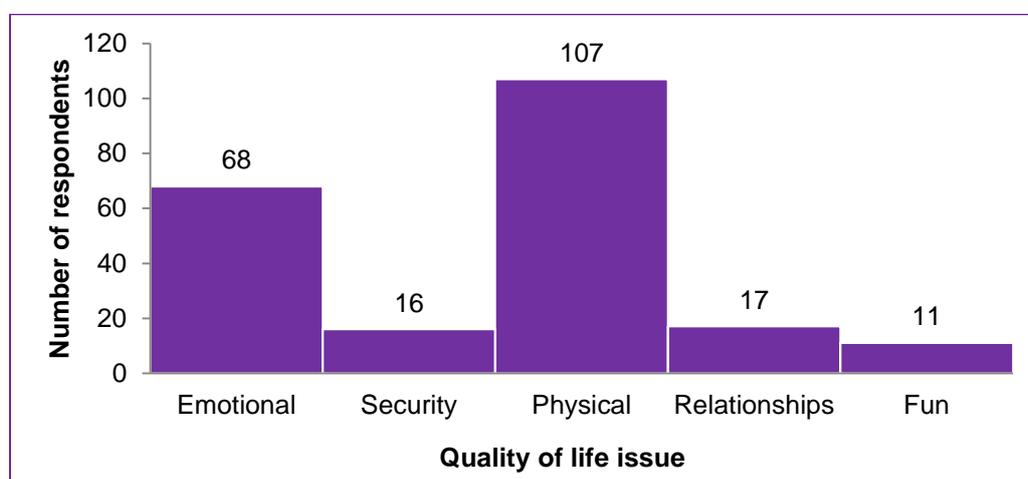
Table 1 – Length of time living with CLL for those in 'watch and wait' and patients post-treatment

	Minimum number of months (years)	Maximum number of months (years)	Average (years)
'Watch and wait'	1.5 (0.1 years)	240 (20 years)	58.17 (4.8 years)
Post-treatment	11 (0.9 years)	288 (24 years)	90.43 (7.5 years)

The following sections will look at the responses for those in 'watch and wait' and those post-treatment.

Pre-treatment results – 'watch and wait'

148 respondents answered the question relating to quality of life issues during 'watch and wait' (question 2). Of these responses, 107 mentioned physical problems affecting their quality of life and 68 people mentioned emotional issues. Security, relationships and fun issues were less frequently reported, as shown in Graph 1, below.



Graph 1 – quality of life issues for those in ‘watch and wait’

The incidence of fatigue and tiredness was the most reported physical issue among ‘watch and wait’ respondents, with 77 people reporting that this issue affected their quality of life. This was followed by immune problems and infections, which affected 39 respondents in ‘watch and wait’, as shown in Graph 2, below.

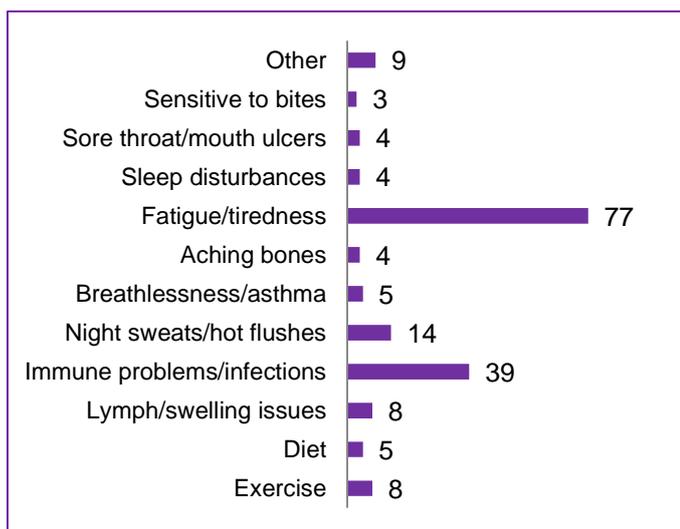
“Extreme fatigue and dealing with trying to avoid infections affect my quality of life” Respondent – 0-2 yrs

For emotional issues, anxiety was the most reported issue, with 58 people reporting that this affected their quality of life. This was followed by depression and feelings of stress (8 and 7 respondents respectively).

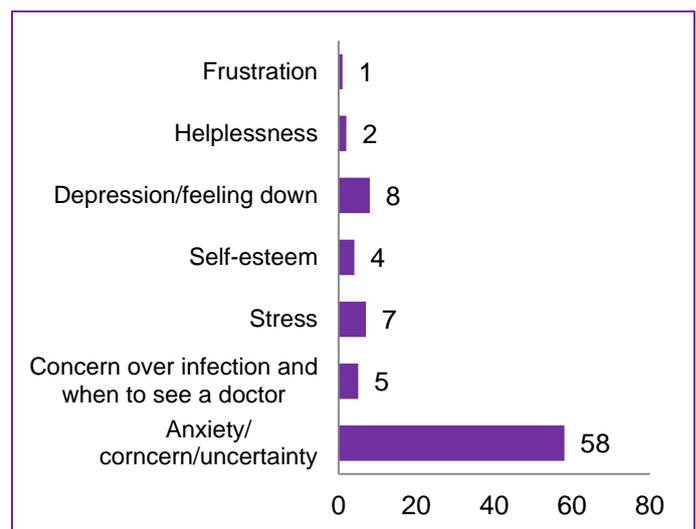
“The uncertainty and the not knowing affect my quality of life” – Respondent 3-5 yrs

Issues relating to security, relationships and fun/social life were less frequently reported but mainly centred around planning for the future (9 respondents), isolation (9 respondents) and the impact on social life (6 respondents).

Physical issues



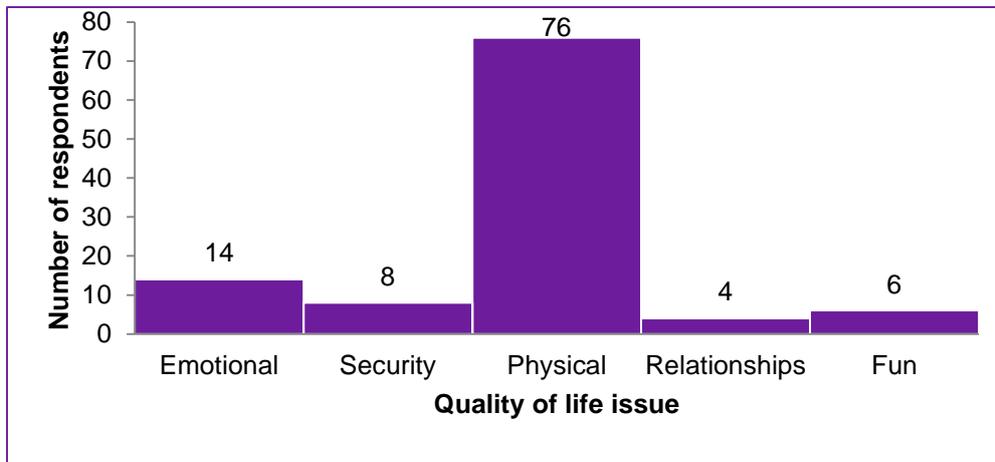
Emotional issues



Graph 2 – physical and emotional issues reported by those in ‘watch and wait’

Post-treatment results

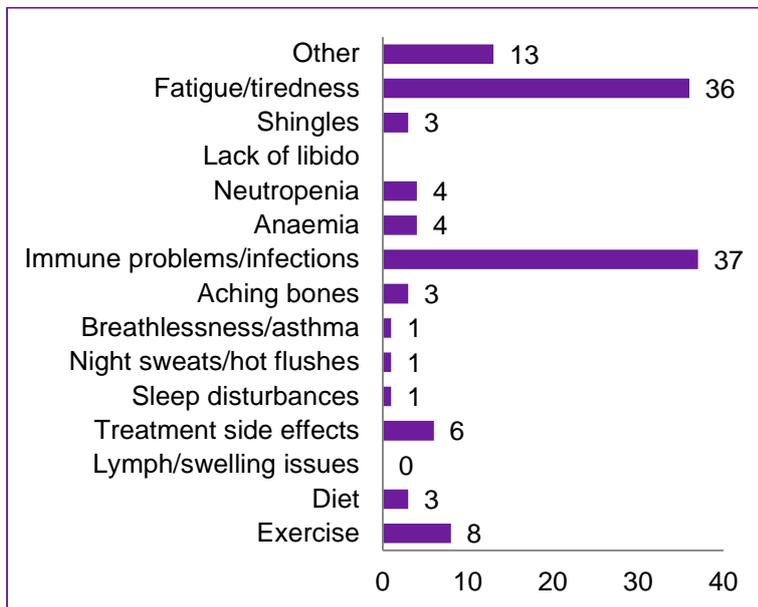
109 respondents answered the question relating to quality of life issues post-treatment (question 4). Similarly to those in ‘watch and wait’, physical problems were the most frequently reported quality of life issue with 76 people reporting this. Graph 3, on the next page, shows that emotional issues were less frequently reported, as were issues to do with security, relationships and fun.



Graph 3 - quality of life issues for those post-treatment

For those post-treatment, the most commonly reported physical issue was infections, which was reported by 37 respondents. This was closely followed by fatigue/tiredness, which was reported by 36 respondents, as shown in Graph 4.

“After chemo, I contracted pneumonia which made it very difficult to do all the things I used to do” – Chemotherapy respondent 9+ yrs



Graph 4 - physical issues reported by those post treatment

Similarly to those in ‘watch and wait’, issues around security, relationships and fun/social life were less frequently reported but mainly centred around work (6 respondents), family (2 respondents) and the impact on social life (4 respondents). Furthermore, unlike for those in ‘watch and wait’, emotional issues were also less frequently reported, with anxiety being the most reported issue (8 respondents).

Discussion

Overall, physical issues were the most reported quality of life issues across both 'watch and wait' patients and post-treatment patients. However, while fatigue/tiredness was the most reported physical issue in 'watch and wait' patients, infections were the most commonly reported physical issue post-treatment. This suggests that patients may have different information needs depending on whether they have had treatment or not. Watch and wait patients may need support and advice on how to manage fatigue and furthermore both post-treatment and watch and wait patients may benefit from advice on how to manage infections. In addition, anecdotal responses suggest that all 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.

The incidence of emotional quality of life issues was high among the 'watch and wait' group (68 respondents) but dropped in the post-treatment group (14 respondents). In the 'watch and wait' group, respondents experienced feelings of anxiety and concern about living with CLL.

Quality of life problems relating to security, relationships and social life/fun were low among both groups. However, this could be due to the survey design which allowed free text responses only (no pre-defined lists/triggers to consider issues in these areas). Therefore issues around security, relationships and fun could be perceived to be secondary issues (with the physical or emotional issues being primary issues).

Taken together, the incidence of quality of life 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, would be managed by the most suitable healthcare professional. Furthermore, this would ensure that patients receive the best possible treatment, management and care for their health needs.

In order to further investigate the quality of life issues of those living with CLL, it is recommended that another survey is conducted, based on the learnings from the present survey. A follow-up survey would allow for further exploration of the physical and emotional impact of living with CLL, particularly what support and advice people living with CLL have received. In addition, it would be valuable to capture demographic responses, such as age, ethnicity and lymphocyte count in order to separate out issues related to older age and issues associated with disease progression. Finally, a follow-up survey would allow a deeper analysis of the issues related to security, relationship and social life/fun, in order to find out how CLL affects quality of life beyond the physical issues.
