CLL - is treatment getting better?

The SEER database is a wonderful tool for understanding cancer and the recent release of hematological data from 1973 to 2004 has prompted several studies including one in last month's Blood (2008; 111:4916-21) by Brenner et al from Heidelberg, Germany and Cornell, New York. The suggestion in this paper is that long term survival expectations of patients with CLL have substantially improved over the past two decades.

Without wishing to discourage readers I am suspicious that this claim is at best exaggerated.

The SEER database is assembled from cancer registries in Connecticut, New Mexico, Utah, Iowa, Hawaii and Atlanta, Detroit, Seattle-Puget Sound and San Francisco-Oakland. It takes in about 30 million people. There were 20,491 cases of CLL diagnosed between 1974 and 2004, 12,120 men and 8371 women. There was a steady increase in the number of cases: 3642 between 80/84, 3969 between 85/89, 4236 for 90/94, 4191 for 95/99 and 4454 for 00/04. The changes in the age groups was rather strange. In the period 80/84 to 00/04 there was a 44% increase in the under 60s, a 3% reduction in those aged 60-69, an 18% rise in those aged 70-79 and a 41% increase in the over 80s.

The percentage surviving 5 years has increased over the same period by 6% and the percentage surviving 10 years has increased by 7% The improvement has been seen in both sexes and at all ages except that the 10-years survival if the over-80s has not improved at all.

They have also looked at relative survival, which means how did they do compared to people of the same age and sex who didn't have CLL? Again, here things seem to have improved from 69% to 75% at 5 years and from 46% to 55% at 10 years, but again for the over 80s there's been no improvement.

Now one explanation is that treatment has got a bit better (though with the over 80s only 30% as likely to survive for 10 years as the non-CLL population, things are not good).

However, there have been other changes over the past 20 years. Supportive care has improved, for example. It may be that we are better able to keep people alive who have CLL even if we can't do much to treat the disease.

Cancer Registries are notoriously poor at collecting cases of CLL. Patients are often not admitted to hospital, and there is usually no histology. Furthermore, the fact that the patient lived with CLL that never caused him any problems is often omitted from death certificates.

But I think that the biggest difference has been in the diagnosis of CLL. Immunophenotyping has meant that patients with lymphoma with blood spillover are no lnger diagnosed as CLL, and generally these patients had a worse prognosis than cases of CLL. But overshadowing all these is earlier diagnosis. It is interesting that patients under the age of 60 are more frequently diagnosed now. This might be because the disease is appearing at a younger age, but it also might mean that the disease is picked up earlier in its presymptomatic course. Patients might only survive longer now because they are diagnosed earlier. I believe this is very likely to be true. When the study started you needed a lymphocyte count of 15,000 to diagnose CLL, but the rules have changed and now you only need 5,000.