

Population level survival for patients with chronic myeloid leukemia: higher survival in Sweden than internationally- a reply

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To the Editor:

We were happy to read Pulte and Jansen's¹ correspondence to the Editor in which they agree that our recent paper² is highly relevant, and discuss some important implications of this research. In this they describe the improvements seen in, and use of TKIs in, elderly patients, the advantages in utilizing Swedish national registries with high completeness, and how detailed information on treatment, molecular markers and patient characteristics would be valuable.

As discussed in the correspondence, differences in the treatment of elderly patients are likely to explain some of the inconsistencies in results seen in different countries. Data from The Swedish CML registry showed that over 80% of patients diagnosed at 70 years of age or older were treated with TKIs in 2014³. Our results and other estimates of CML patient survival in Sweden⁴ illustrate the positive result of treating older patients with TKIs in Sweden and the potential improvement that could be seen for older CML patients in other countries if similarly treated.

There are major advantages in using population-based data as recognised by Pulte and Jansen who stated that our study "...underscores the importance of complete population level databases in determining how well advances in cancer treatment are implemented on the population level". However, one limitation in our study was the lack of individual level treatment information in the Swedish Cancer Register. We saw improvements in survival for CML patients over time and related these to the changes in treatment/guidelines in Sweden, but without individualised treatment information it is difficult to be certain of the causes for improvement.

Thus, we believe that the next step for research in this area will be to utilize the information-rich data contained in Swedish quality registers such as the Swedish CML registry that was established in 2002. Similar quality registers for other hematological malignancies (acute myeloid and lymphoblastic leukemia, lymphoma, multiple myeloma, chronic lymphocytic leukemia, myeloproliferative neoplasms and myelodysplastic syndromes) have been established and been part of the Swedish Blood Cancer Register since 2007. The overall purpose of the Swedish Blood Cancer Register is to

contribute to increased knowledge of, and improve diagnostics and treatment of, patients with hematological malignancies in Sweden. The CML quality registry contains clinical information including detailed information on diagnostics, treatment, monitoring and outcome. As stated above, this type of information is unfortunately lacking in the Swedish Cancer Registry. Even though reporting to the quality register is not mandatory, the completeness of the CML quality register compared to the Swedish Cancer Register is approximately 95%³. There are already good examples of what can be achieved when utilizing the Swedish CML registry data⁵⁻⁶. In the near future, when longer follow-up of patients is available, the detailed individualised information can be used further to provide a much clearer story, and help identify and quantify causal relationships.

We also believe that one of the major advantages of our study was the use of the measure the loss in expectation of life. The simple interpretation of this measure ensure a broad understanding of the expected survival of chronic myeloid leukemia patients, more so than other measures commonly used, such as relative survival which limits interpretation to a scenario where patients are only able to die due to their cancer.

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