Fear of Progression in Outpatients With Chronic Myeloid Leukemia on Oral Tyrosine Kinase Inhibitors

Jochen Hefner, PhD, Eva-Johanna Csef, MS, and Volker Kunzmann, PhD

Hefner is a consultant of psychosomatic medicine and psychotherapy in the Department of Internal Medicine at the University of Wuerzburg in Germany; Csef is an assistant physician in the Department of Oncology, Gastroenterology, and Infectiology at St. Franziskus Hospital in Muenster, Germany; and Kunzmann is a professor of medical oncology in the Department of Internal Medicine at the University of Wuerzburg.

No financial relationships to disclose. Mention of specific products do not indicate or imply endorsement by the *Oncology Nursing Forum* or the Oncology Nursing Society.

Hefner and Kunzmann contributed to the conceptualization and design. Csef completed the data collection. Hefner provided the statistical support and contributed to the analysis. All authors contributed to the manuscript preparation.

Hefner can be reached at hefner_j@ukw.de, with copy to editor at ONFEditor@ons.org.

Submitted November 2014. Accepted for publication June 28, 2015.

Key words: chronic myeloid leukemia; imatinib; fear; anxiety; distress

ONF, 43(2), 190–197.

doi: 10.1188/16.ONF.190-197

Purpose/Objectives: To assess fear of progression (FoP) in outpatients with chronic myeloid leukemia (CML) on oral tyrosine kinase inhibitors (TKIs).

Design: Prospective and descriptive.

Setting: A university-based outpatient cancer clinic in Wuerzburg, Germany.

Sample: 37 outpatients with CML on oral TKIs.

Methods: FoP was assessed with a questionnaire. Clinical data were extracted from the medical charts.

Main Research Variables: Frequency and contents of FoP.

Findings: Sum scores and levels of FoP in the sample population (N = 37) were as high as in cancer populations with more unfavorable life expectancies. Regarding single items, fear that medication may harm the body was most prevalent, regardless of group affiliation. The actual fear of disease progression was only ranked sixth out of 12 items for the total sample and was ranked second by the second-generation TKI group.

Conclusions: In a sample of outpatients with CML, FoP was frequent and most often generated by fears of treatment side effects.

Implications for Nursing: Nurses should be vigilant about FoP in this population. Established questionnaires may help to identify and evaluate this frequent source of distress. Specific communication could reveal unmet informational needs and may help to initiate interventions. Additional studies are needed to confirm the numbers in a larger cohort of patients, to examine the prevalence during the course of disease, to search for potential influences on the outcome (i.e., via adherence), and to extract the best interventions.

Chronic myeloid leukemia (CML) is a malignant hematologic disease caused by genetic mutation in hematopoietic stem cells in the bone marrow (Apperley, 2015; Jabbour, Bixby, & Akard, 2012; Jabbour & Kantarjian, 2014). The growth of malignant cells leads to a number of unspecific symptoms, such as fatigue, weight loss, night sweats, or fever. As a result of the clonal proliferation of malignant cells in the bone marrow, the suppressed normal hematopoiesis may lead to hepatomegaly, easy bleeding, and frequent infections (Apperley, 2015; Jabbour, Bixby, et al., 2012; Jabbour & Kantarjian, 2014). Three phases of CML can be described. Most patients present in the chronic phase with fairly stable symptoms and pathologic blood counts. Without treatment, CML will progress into an accelerated phase and, eventually, into an acute leukemic-like stage or so-called blast crisis (Apperley, 2015). Reports of medicinal treatment alleviating symptoms date back to the 19th century (Thompson, 1877), and treatment options showing improved survival were available in the 1970s when interferon alpha and allogeneic stem cell transplantation were implemented (Baccarani et al., 2002; Bonifazi et al.,