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8 Information needs of patients with a haematological malignancy; a cross-sectional study

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Introduction: In 2008, 7065 patients were diagnosed with a haematological malignancy in the Netherlands, which represents 7.8% of all new cases of cancer. Haematological malignancies present some important differences with solid cancers. Quite often therapy has to start within days or even hours after diagnosis, which challenges adequate information provision. Knowledge about the information needs of these patients is lacking.

Aim: Obtaining insight into the information needs of patients with a haematological malignancy, predictors

associated with need for information and patient satisfaction with current information procedures. Furthermore, the relation between information satisfaction and quality of life was studied.

Materials and methods:

Patients with a haematological malignancy visiting the Haematology outpatient clinics of VUmc and MCA were included.

To measure the information needs, a questionnaire was composed using existing validated instruments: The Toronto Information Needs Questionnaire-Breast Cancer (TINQ), the Patient Learning Needs Scale (PLNS) and the Patient Information Need Questionnaire (PINQ). Items are categorized regarding need for information on disease, diagnostic tests, treatment, complications and symptoms and psychosocial aspects.

Satisfaction with the current patient information was measured by the Information Satisfaction Questionnaire. Health related quality of life was assessed with the EORTC-QLQ-c30. Co-morbidity was measured with the ACE-27. Furthermore, information on demographic and disease related parameters were collected.

Results: 458 patients returned the questionnaire (66.3% response rate). The information need was higher for disease and treatment-related information as compared to psychosocial information (TINQ $p \leq 0.001$, PLNS $p \leq 0.001$, PINQ $p \leq 0.001$).

Predictors of a high overall need for information were: younger age (TINQ $p = 0.007$, PLNS $p = 0.010$, PINQ $p = 0.006$), female gender (TINQ $p = 0.029$, PLNS $p = 0.045$, PINQ $p = 0.110$), membership of a patient association (TINQ $p = 0.169$, PLNS $p = 0.022$, PINQ $p = 0.002$).

Multivariate regression analyse showed predictors of higher information needs: younger age (TINQ $p = 0.028$, PLNS $p = 0.006$, PINQ $p = 0.003$), better quality of life (PLNS $p = 0.002$, PINQ $p = 0.008$), membership of patient society (PINQ $p = 0.003$) and moderate co-morbidity (PLNS $p = 0.007$).

Patient satisfaction with the provided information was good (mean score 17.34, SD=3.20, range 6-24). Higher satisfaction was associated with better quality of life ($p = 0.000$).

Conclusion: Patients with haematological malignancies had a higher need for information regarding disease and treatment as compared to psycho-social information. Information need was related to several variables. A prospective study is needed to obtain insight into information needs from time of diagnosis to cancer survivorship or end of life. To realise this, a questionnaire will be developed, based on the **Results** of the present cross-sectional study.