

Patients with advanced cancer do not mind participating in longitudinal study on prognostic awareness

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BACKGROUND

The research in palliative care has ethical controversy due to patients' vulnerability and due to limited access to this population caused by the phenomenon of gatekeeping. On the other hand, according to ethical principles of research, everyone should get the opportunity to participate in research. Previous studies show that patients do not mind participating in research so the aim of this study is to provide information about the evaluation of participation in a longitudinal study on prognostic awareness.

AIM

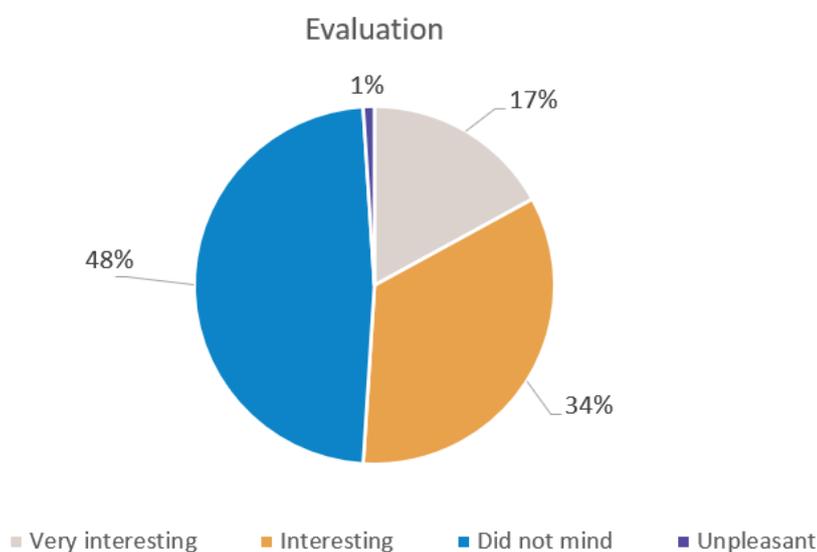
The aim of this study was to explore how patients feel about their participation in a longitudinal study on prognostic awareness.

METHODS

This was a multi-center longitudinal cohort study in patients with advanced cancer and limited prognosis (assessed by 12-months surprise question) from IMPAC project. Patients (n=135) were asked three times to complete structured interview containing questions about their level of prognostic awareness, quality of life and also asking how pleasant or unpleasant was being part of this study on 5-point Likert scale. Data were analysed using nonparametric Spearman's correlation, Mann-Whitney and Friedman test in IBM SPSS 26.

RESULTS

Half of the sample (48 %) did not mind participating in this research, 34 % of patients found it interesting and 17 % as a very interesting experience. The answers were not associated with sex, education, quality of life or pain but were associated positively with being faithful ($Z = -3.4$; $p = 0.001$) and having higher age ($R = 0.2$; $p = 0.03$). **The evaluation of first wave was not different in patients who did not continue (N=103) against patients who completed all measurements (N= 44; $Z = -0.29$; $p = 0.8$).** In the group of patients who completed three waves there were no significant difference between ratings of repeated measurement (N= 44; $\chi^2 = 2.9$; $p = 0.2$).



DISCUSSION

Majority of advanced cancer patients do not mind participating in research about prognostic awareness with longitudinal design a half of them found it as interesting experience. Thus, it seems that patients who do not like to be part of the research are able to refuse it.

