

Patient's Decisional Control Preferences in the Palliative Care Setting: a Multi-center Survey. Result from Brazil population.

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BACKGROUND: The way that patients and doctors make decisions on health treatments have been changing as acknowledgement of patient participation is increasing. The information and communication needs of patient and families still requires deeper understanding, especially in palliative care setting. In addition, how actively patients want to participate in making decisions concerning their cancer care remains controversial. Participation of treatment decision making is influenced by many factors including cultural background, demographics and the severity and uncertainty of the disease process. The primary objectives of this study was to determine the preferences regarding passive decision-making and information disclosure among palliative care patients. The secondary objectives were to determine whether agreement between patients' passive decision making preference and actual decision making process influences their satisfaction with the care, and to explore whether patient passive preferences are related to variations in demographic factors in a sample of patients attended in a Brazilian Palliative Care Unit.

HYPOTHESIS: We hypothesize that there will be overall regional differences in decisional control preference with a lower overall percentage of passive decision control in developed regions compared to developing regions. We also hypothesize that older, male patients with lower socio-economic status (education), express more desire for passive decision making.

METHODS: Social demographic data was recorded in order to establish the profile of the sample studied. The "Decision Making Preference Questionnaire" (DMPQ) was applied, to check how patients prefer to make decisions. In addition, the "Satisfaction with the Decisions and Care Questionnaire" (SWDC) was applied to check how satisfied patients were with the way that decisions were made. Finally the Illness understanding questionnaire was also applied in order to verify if the patient was aware of his/her actual disease situation. Eligibility criteria were: 1) Patient with advanced cancer; 2) Patient is 18 years old or older; 3) Patient with normal cognitive status; 4) Patient willing to participate in the study and sign informed consent; 5) Patient seen by palliative care team for at least one visit; 6) Patient has resided in Brazil for at least 5 years. Exclusion criteria was: 1) Patient refusal in participating in the study.

RESULTS: One Thousand, six hundred ninety one patients were addressed. Two hundred and forty two were enrolled and finished the study. The main reason for drop out was be at palliative care unit for the first time (35,6%), followed by inability to answer (16,7%) and have no advanced cancer (16,3%). Among the reasons for being unable to answer were be illiterate, have low cognition, be in delirium or have neurological or psychiatric disorder. In our sample, 73,5% of those patients who finished the study prefer to make decisions by themselves.

CONCLUSIONS: Among advanced cancer patients who are in palliative care and are aware of their condition, the majority will prefer to make decisions by themselves.