

Difference in informational needs of patients with advanced disease and their caregivers. A secondary data analysis.

Center for palliative care
Prague/ Czech Republic

Anna Tučková, Karolína Vlčková, Adam Houska, Kristýna Poláková, Martin Loučka

The work was supported by grant No. 17-26722Y, Czech Science Foundation.

BACKGROUND

Informing patients about their illness and prognosis is necessary for successful advance care planning. This study is based on data from a cross-sectional survey of seriously ill patients and their caregivers (physicians and family members) who were asked to rank 40 items, related to end of life care, based on their importance. **As patients ranked item "Get information from the doctor even if it is bad" significantly higher than the caregivers, the aim of this study was to explain this difference**

METHODS

Analysis was conducted separately for each data set - physicians and family caregivers (n=221) and patients (n=170). Factor analysis was used for general data interpretation.

RESULTS

In the patient group 8 factors were found (KMO=0,749, explaining 63 % of variance) with the distribution of items connected to informational needs concentrated to one factor explaining 10,7 % of variance. In the caregiver group were identified 9 factors (KMO=0,820, explaining 62 % of variance). Five items related to informational needs are not connected so closely to each other but additionally they relate to items of privacy, individuality and family relationships. The distribution of the items connected to the informational needs into the factors is presented below:

PATIENTS RESPONSES ARE CONCENTRATED TO 1 FACTOR

Having information about time prognosis
Having information about illness trajectory
Get information from a doctor even if they are bad
To decide how much information about health status one wants to get.
Having enough time for talking to doctor

CAREGIVERS RESPONSES ARE SPREAD INTO 2 FACTORS

Having enough privacy for conversation with the doctor

Having enough time for talking to doctor

To be perceived as a person, not just a patient

Having information about illness trajectory

Get information from a doctor even if they are bad

Believing family is not informed behind ones back

Having information about time prognosis

To decide how much information about health status one wants to get.

CONCLUSION

One of the reasons why patients' ranking of informational needs differ from caregivers could be that their needs are connected to different aspects of end-of-life care. **Our analysis shows that while patients focus on what they want to know, their caregivers focus on how the information should be delivered.** As caregivers are usually the main source of information for patients, this discrepancy could cause misunderstanding in advance care planning.

