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How do Hospice Patients Feel about Hospice Care - and is It Important? Exploring the Relationship between Patient Attitude to Hospice Care, Survival and other Patient Characteristics in the Setting of First Croatian Hospice (Original paper)

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Original Article

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Abstract:

Objective: To research the relationship between the initial attitude of hospice patients towards hospice care and different patient characteristics.

Design: Retrospective chart review.

Participants: 433 consecutive patients with the determined attitude towards hospice care, in the first Croatian hospice, the Marija K. Kozulić from March 2013 to March 2016.

Methods: We evaluated the relationship between patient attitude towards hospice care and characteristics such as age, gender, marital status, level of education, the presence of cancer, performance status, initial and final opioid dose, the use of anxiolytics and antipsychotics, fluid intakes, participation in physiotherapy, discharge status and survival in hospice.

Results: Patients were divided into four different groups based on their attitude towards hospice care: acceptance, rejection or anger, depression, bargaining or adapting, and uninformed or partially informed. Our research shows that the majority of patients (69%) has a positive attitude towards hospice. There were no significant differences regarding age, gender, marital status, as well as survival and discharge status between the groups. However, patients exhibiting depression, bargaining or adapting had significantly higher opioid doses in therapy (on average, 145.8 mg OME/day), and the highest elevation of opioid doses during their stay (on average, 52 mg OME/day) compared to other groups.

Conclusion: Most patients have a positive attitude towards hospice care. However, the differences in attitude might not influence the length of survival or discharge percentage. However, patients exhibiting depression, bargaining or adapting might be in risk of over-treatment with opioids and could potentially gain significant benefits from the addition of anti-depressants, or sessions with a psychologist.

Conflict of interest:

The authors declare no conflict of interest.

Statement of Informed Consent and Human Rights The study is a retrospective chart review and does not in any way offer any identifying information regarding patients and offers complete anonymity and does not require informed consent. The

study was performed only after approval from the Ethics Committee of the Marija K. Kozulić Hospice and was conducted by the ethical standards and with the Helsinki Declaration.

Introduction

Hospice is an institution where terminal patients are provided with palliative care with the primary goal of enhancing the quality of life as much as possible. Enrolling into a hospice is a stressful and potentially traumatic choice for both, patients and their families. Among other issues regarding hospice care, it is important to examine the attitudes of the patients entering hospice as such information might be used to assess the need for a Psychologist or Spiritual Guide in terminal care and to help in prescribing different medications.

However, to the best of our knowledge, there is a scarcity of data on such topic, and no such information for the Eastern European region. Adenipekun *et al.* showed that the majority of Nigerian patients did not have any knowledge about hospice and palliative care which might be responsible for different expectations when entering the hospice, although 87% of patients agreed that establishing a hospice is necessary (1).

A study by Azami-Aghdash (2) *et al.* described a similar percentage of patients and health care providers with a positive outlook towards hospice care (79%). Catt *et al.* found that attitude to hospice is unaffected by the position in society or fears from death, with similar views between different age groups (3).

We aimed to determine whether patients who are more receptive towards hospice care live longer on average and whether, there is a higher percentage of discharge among patients who are not receptive of hospice care.

Patients and methods

Our study is a retrospective analysis of 433 consecutive patients at the Marija K. Kozulić Hospice in Rijeka, Croatia,

for whom an attitude towards hospice care was noted and described. The study includes patients who were hospitalized in the only Croatian hospice from March 2013 to March 2016. The hospice offers 14 beds divided into single and double rooms. Patient groups were divided into four main subgroups with a similar attitude, to prevent splitting into too few groups which would make statistical analysis more difficult.

Opioid doses were based on McPherson's Guide (4) and expressed as oral morphine equivalent (OME). Performance status (PS) is based on the *Croatian Patient Categorization System* and upon the level a patient requires, with PS 1 meaning patients with low level of dependency, and PS 4 describing the bedridden patient. The system resembles the *Eastern Cooperative Oncology Group Classification*, with 0, 1 and four being the same (5,6).

Statistical analysis was performed using Statistica 12 Software (StatSoft, USA). A p-value of less than <0.05 was considered statistically significant. The study was performed after permission was obtained from the Ethics Committee of the Marija K. Kozulić Hospice.

Results

A total of 433 hospice patients from March 2013 to March 2016 were examined. Genders were equally represented, with 218 female patients (50%), while the average age was 70.9 years (± 12.7 years), and the average performance status was 3.25 out of 4. A majority of patients had cancer as the reason for admittance (90%).

A total of 58 (13%) of patients were discharged due to various reasons, which were not explicitly mentioned. Active physiotherapy was performed in 149 (34%) patients. Patients used, on average, 6.2 different

medications, while anxiolytics and antipsychotics were used by 224 (52%) and 129 (30%) respectively. Average opioid dose on admittance was 94.9mg OME/day rising to an average final dose of 124.3mg OME / day.

We have divided patients into five different categories based on their attitude towards hospice care: acceptance group; rejection/anger group; depression; bargaining or adapting (DBA) group; and uninformed or partially informed (UPI) patients.

We found no significant difference between the groups regarding age, gender, cancer percentage, marital status, the highest level of education, number of medications and fluid intake on day 1, 7 or night 1 (**Table 1**). There was a difference in performance status with, unsurprisingly, the UPI group exhibiting the lowest scores among all groups.

Between the two largest groups, patients who are in acceptance towards hospice care, and patients who expressed rejection and anger, there are no significant differences among any of the explored characteristics. A difference exists among patients exhibiting DBA and acceptance. There is a notable difference in opioid use between the DBA and the acceptance group, with the DBA group using a significantly higher opioid dose, both initially and finally. Also, a difference was seen in elevation of opioid doses during the hospice stay between DAB (on average, elevation of 52 mg OME/day) and all other groups (elevation ranged, on average, from 23-34 mg OME/day). On the other hand, the DBA group used fewer antipsychotics and anxiolytics than any other group. We have also noted a possibility that uninformed patients might be under-dosed with opioids before entering the hospice (**Figure 1**).

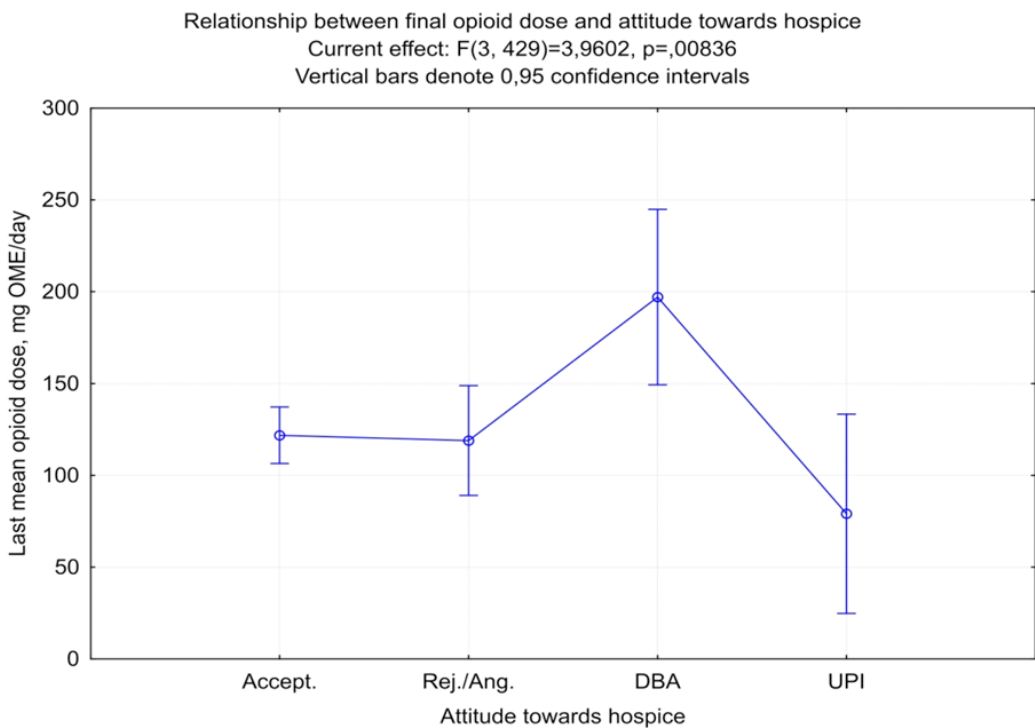
Table 1: Patients characteristics in different attitude groups, N=433.

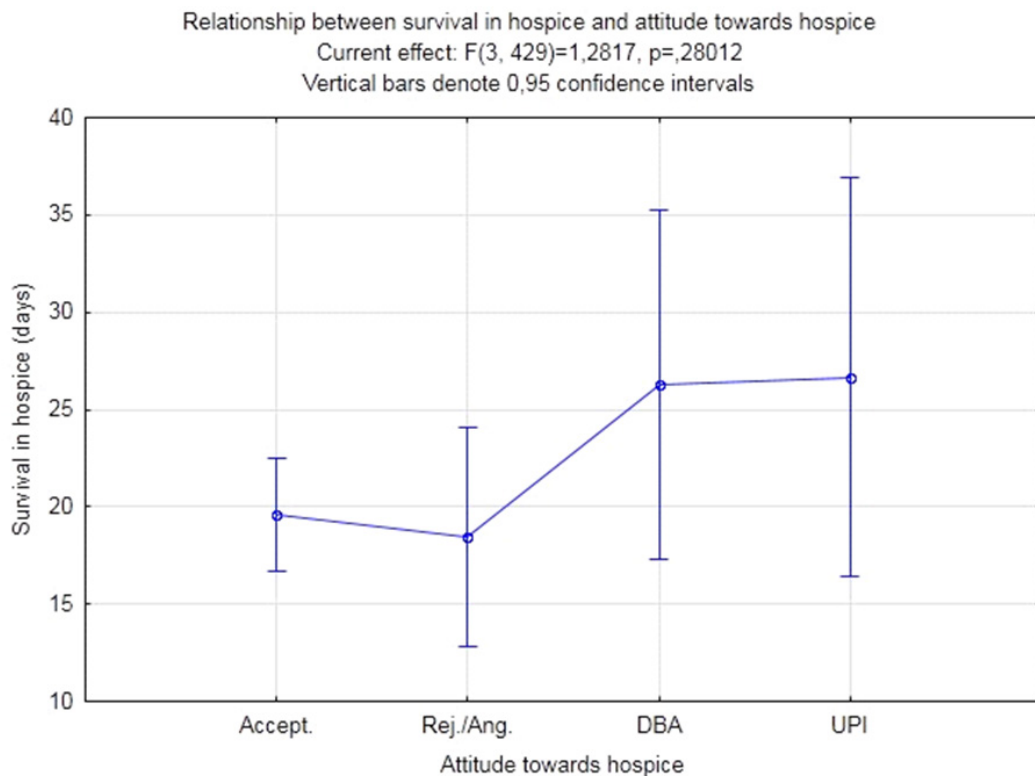
| Characteristics | Initial attitude toward hospice care | | | |
|--|--------------------------------------|--------------------|------------------------------------|---------------------------------|
| | Acceptance | Rejection or Anger | Depression, bargaining or adapting | Uninformed / partially informed |
| Total number | 299 | 79 | 31 | 24 |
| Average age (years) | 70.7 | 71.1 | 69.6 | 74.7 |
| Females (%) | 152 (51) | 40 (51) | 14 (45) | 12 (50) |
| Cancer patients (%) | 273 (91) | 68 (86) | 27 (87) | 21 (88) |
| Married (%) | 142 (47) | 40 (51) | 14 (45) | 10 (42) |
| College highest level of education (%) | 64 (21) | 15 (19) | 4 (13) | 6 (25) |
| Initial opioid dose (OME / day) | 93.5 | 95.4 | 145.8 | 44.9 |
| Final opioid dose (OME / day) | 121.8 | 118.9 | 197.1 | 79.06 |
| Antipsychotic use | 90 (30) | 26 (33) | 6 (19) | 7 (29) |
| Anxiolytic use | 155 (52) | 43 (54) | 13 (42) | 13 (54) |
| Number of medications | 6.2 | 6.4 | 5.6 | 5.7 |

| | | | | |
|---|------------|------------|------------|------------|
| Intake day 1 (ml) | 670 | 597 | 606 | 708 |
| Intake night 1 (ml) | 361 | 270 | 347 | 354 |
| Intake day 7 (ml) | 858 | 808 | 796 | 1092 |
| Performance scale | 3.2 | 3.4 | 2.9 | 3.8 |
| Active physio-therapy sessions (%) | 112 (37) | 21 (27) | 10 (32) | 6 (25) |
| Discharged (%) | 40 (13) | 8 (10) | 5 (16) | 5 (21) |
| Length of stay (days)* | 15.8 | 15.7 | 18.8 | 18.9 |
| Bolded text signifies p value < 0.05. OME = Oral Morphine Equivalent. Ml = milliliter. *Only deceased patients were analyzed, N= 373. | | | | |

Our results also show that patients who are in acceptance towards palliative care might perform active physiotherapeutic exercises more often (37% vs. 25-32%).

Surprisingly, however, there was no difference in survival between the four groups (**Figure 2**). There was a trend towards a higher number of discharges among uninformed or depressed patients, but the result did not reach statistical significance.





Discussion

The study is one of largest retrospective studies examining attitudes of actual hospice patients towards hospice care and is part of a larger study examining the effects of different medications on the same, but larger population (7).

Most patients who arrive at hospice are reconciled with themselves and accept palliative care in hospice with a positive standpoint. However, at least a third of the patients are in different stages of grief, signifying the need for a Psychologist or Spiritual Guide along with medication and supportive care.

Our research shows that acceptance and rejection/anger group did not significantly differ in any of the analyzed characteristics. However, the DBA group exhibited a significantly higher average opioid dose than other groups - both initially and finally. This

group also had the highest elevation of opioid dose during the hospice stay. However, the same effect was not present in antipsychotic and anxiolytic use. It is known that depression and related conditions might emphasize pain (8), and we propose a hypothesis that screening for attitude towards hospice care might identify patients in which adjuvant treatment with medications such as antidepressants and psychologist sessions might achieve success and consequently lower opioid dose (9).

Age, marital status, level of education or cancer diagnosis did not significantly affect attitudes towards hospice care. Also, we did not confirm our primary hypothesis as different attitudes were not associated with a shorter stay in hospice. Although UPI and DBA patients were more likely than average to be discharged from hospice, the trend did

not reach statistical significance, but this result is intriguing and offers valuable insight for further research.

The shortcoming of this research is the lack of information for almost a quarter of total patients, which were in many cases comatose or somnolent; therefore no clear data can be concluded. Also, this study suffers the critique standard for all retrospective studies, offering correlations without causality. We should also note that only initial attitude of patients was described. We did not note whether there was a change in initial attitude which might also be very important for a more accurate analysis. Also, the attitude described is a subjective analysis of the interviewer, and may also depend on the current mood of the patients, which might not represent a correct attitude.

However, this is one of the largest retrospective analysis published so far in the hospice setting which analyzes attitude and different patient characteristics, and to the best of our knowledge, the first of its kind in the eastern European countries. It provides new insight into patient position; describes differences in opioid use between patient groups; offers plausible hypotheses for further studies.

Conclusion

Placing a higher emphasis on patient attitude when entering hospice might be useful as patients who exhibit signs of depression, bargaining or adapting suffer the risk of over-treatment with opioids. Such patients should be offered psychological and spiritual support, and they could potentially have the highest gain in using adjuvant analgesic therapy and antidepressants, which could lower the need for high opioid dose and thus avoid opioid side-effects. Our research also notes that the attitude towards hospice care might also influence a percentage of patients included into active physiotherapeutic

exercises. However, no difference in survival or discharge rates between the groups with a different attitude towards hospice care was observed.

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