



Research Article

US and Russian physician perspectives regarding end of life care

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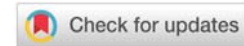
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Abstract

Purpose: To compare US and Russian primary care physicians' attitudes, comfort and experiences providing palliative care.

Design: Cross sectional survey.

Settings: Iowa, USA and Leningrad Oblast, Russia

Participants: Family medicine physicians at University of Iowa and Northwestern State Medical University, St Petersburg, Russia, community practicing family physicians.

Methods: Chi-squared testing for dichotomous variables and t-tests for mean scores.

Results: Sixty-six US and 81 Russian physicians completed the survey. More US physicians preferred the home setting for care (83% vs 56%) $p < .001$ and Russian physicians community hospice (47% vs 18%) $p < .001$ weeks to months before patient's death. Ninety-four percent of US physicians reported that patients should make end of life decisions, 57% of Russian sample reported that family physicians should make those decisions $p < .001$. Patient should be informed (US vs Russia) of terminal illness Always (74% vs 31%) $p < .001$ and If Asked (9% vs 64%) $p < .001$. US physicians reported higher comfort rates with managing symptoms except for pain management (88% vs 100%) $p = 0.001$. Drug prescribing comfort favored US physicians. In the last 6 months Russian physicians made more home visits "Often or Always" 73% vs 6%, $p < .001$ and US physicians disclosed poor prognosis "Often or Always" 83% vs 56%, $p < .001$ and were more satisfied with provided care "Often or Always" 63% vs 36%, $p = 0.002$.

Conclusions: US sample was more concerned with patient autonomy and had more comfort and satisfaction in providing end of life care.

Introduction

The World Health Organization (WHO) predicts that by 2040 15% of the world population will be age 65 years or older [1]. Primary care physicians will be treating this aging population and by necessity will be exposed to end of life care demands. Culture of the provider, patient, social environment and policies of the health care system will influence the delivery of end of life care. WHO classifies Russia and 73 other countries as having isolated palliative care provisions and 20 countries including the United States as having advanced integration of palliative care [2].

There have been few studies conducted among US physicians

[3] and among Russian physicians [4] regarding end of life care. No research to our knowledge addresses differences between US and Russian primary care physicians' attitudes, comfort or experiences regarding end of life care. The purpose of this study is to compare primary care physicians' end of life care attitudes, comfort and experiences when practicing in isolated (Russia) versus integrated (US) palliative care health systems.

Methods

A total of 116 US family physicians, either faculty in the University of Iowa department of family medicine or in attendance at the 2018 Annual Refresher Course and 102 Russian general practitioners from either the Northwestern



State Medical University department of family medicine or in attendance at one of three conferences in St Petersburg or Gatchina, Russia were invited to participate in this anonymous survey. Questionnaires were distributed during the start of each conference and completed questionnaire were collected at the end of the conferences by the principle investigator. Departmental faculty at the University of Iowa and the Northwestern State Medical University were provided the questionnaire by departmental mail and the completed questionnaires were received by the departmental investigator by the same route. No palliative care topics were discussed during the conferences.

A 21 item questionnaire was developed using questions from existing studies [3,5]. Items included were: gender, years in practice, questions related to best settings for care of terminally ill patients, decision making, physicians' personal preferences for end of life care if they had a terminal illness, comfort in managing symptoms and prescribing medications for terminally ill patients and practice experiences with end of life care over the last six months. An open ended question concluded the questionnaire, which asked for obstacles encountered while caring for terminally ill patients. The questionnaire was translated from English to Russian, back translated by a native Russian speaker and reviewed for content validity [6].

Data analysis

Preliminary descriptive analyses were performed for all variables. The responses that used a 5-Likert scale were combined into two categories (always/often, and sometimes/rarely/never). For those questions with multiple answer selections, each answer was analyzed as a dichotomous variable. Unpaired t-test was used to compare continuous variables between the two cohorts. The Pearson chi-square test or Fisher exact test were used to compare categorical variables between groups (Total US and Russian physician as well as the sub-groups of US and Russian community practicing physicians). Analyses were also completed controlling for gender. All P-values were 2-tailed, and results were considered statistically significant at P-values less than 0.05. All analyses were performed using SAS version 9.4 (SAS Institute Inc. Cary, NC).

Data for the open response question were analyzed using systematic content analysis [7] completed by 3 US investigators. Initially, each of the investigators individually codified these open responses. Total number of themes ranged from 9 to 37. Following individual analysis, the group met for discussion of overarching themes and identified 5 main groups through discussion and consensus. The identified themes were family issues of care, lack of resources, communication, organizational and educational issues.

Results

One hundred and forty-seven physicians completed the questionnaire; 66 of 116 US physicians (response rate 57%) and 81 of 102 Russian physicians (response rate 79%). Significantly more female and community physicians were in the Russian

cohort (Table 1). Home was the preferred location for end of life care with larger percentage of Russian physicians also choosing community hospice, weeks to months before death (Table 2). Controlling for gender, hospital choice for care by family became significant a $p=0.036$ favoring US physicians.

Table 3 lists options for end of life decision making. Controlling for community physicians the difference in parents as decision makers is no longer significant $p=0.173$. Difference in using the physician's judgement to decide to inform the patient of terminal illness is no longer significant when controlling for gender $p=0.129$. When controlling for gender, the supportive care choice for terminal illness became significantly different $p=0.035$ favoring Russian physicians.

The results for comfort in managing and prescribing for end of life symptoms are showed in Table 4. Comfort in prescribing sedatives is no longer significantly different when controlling for community physicians $p=0.055$ and gender $p=0.077$.

Physician practice experiences listed in Table 5 reveal that Russian physicians made more home visits and US physicians were more satisfied with the care they provided to terminally ill patients. US physicians disclosed poor prognoses more often. When analyzing variable "patient dies with dignity" using only community based physicians, there was significantly more US

Table 1: USA and Russian Physician Characteristics.

| | Community Physicians | | | Total Physicians | | |
|-----------------------------|----------------------|-------------|---------|------------------|-------------|---------|
| | USA | Russia | P value | USA | Russia | P value |
| | N (%) | N (%) | | N (%) | N (%) | |
| Female | 15 (32) | 55 (80) | <.001* | 31 (47) | 65 (81) | <.001* |
| Practice Setting: | | | | | | |
| Resident | | | | 17 (26) | 5 (6) | |
| Academic | | | | 18 (27) | 7 (9) | <.001* |
| Community | | | | 31 (47) | 69 (85) | |
| Total | | | | 66 (100) | 81 (100) | |
| Mean Years in Practice (SD) | 24.6 (11.6) | 19.3 (11.3) | 0.034** | 19.3 (11.3) | 18.0 (11.5) | 0.408** |

* chi-square
** t-test

Table 2: Best Care Setting for Terminally Ill Patients.

| | Setting | Physicians Answering YES* | | | | | | |
|--|---------------|---------------------------|---------|---------|------------------|---------|---------|--|
| | | Community Physicians | | | Total Physicians | | | |
| | | USA | Russia | P value | USA | Russia | P value | |
| | | N (%) | N (%) | | N (%) | N (%) | | |
| Expected Death Days to Weeks | Home | 22 (71) | 42 (61) | 0.375 | 53 (80) | 50 (62) | 0.014 | |
| | Hospital | 0 (0) | 1 (1) | >.99 | 0 (0) | 2 (2) | 0.502 | |
| | Community | 10 (32) | 27 (39) | 0.655 | 14 (21) | 31 (38) | 0.026 | |
| | Hospice Other | 3 (10) | 0 (0) | 0.028 | 6 (9) | 0 (0) | 0.007 | |
| Expected Death Weeks to Months | Home | 26 (84) | 36 (52) | 0.003 | 55 (83) | 45 (56) | <.001 | |
| | Hospital | 0 (0) | 1 (1) | >.99 | 0 (0) | 1 (1) | >.99 | |
| | Community | 5 (16) | 35 (51) | 0.001 | 12 (18) | 38 (47) | <.001 | |
| | Hospice Other | 4 (13) | 2 (3) | 0.072 | 5 (8) | 2 (2) | 0.244 | |
| Physician's Assessment of Family Members' Choice | Home | 13 (42) | 45 (65) | 0.029 | 27 (41) | 51 (63) | 0.008 | |
| | Hospital | 9 (29) | 12 (17) | 0.186 | 23 (35) | 17 (21) | 0.060 | |
| | Community | 7 (23) | 18 (26) | 0.708 | 13 (20) | 21 (26) | 0.373 | |
| | Hospice Other | 4 (13) | 0 (0) | 0.008 | 6 (9) | 0 (0) | 0.007 | |

*may have answered YES to more than one choice



Table 3: End of Life Decisions.

| | Who is Alternate Decision Maker for Married Unresponsive Patient? | | | | | | | | | |
|----------------|---|------|--------|------|---------|------------------|------|--------|------|---------|
| | Physicians Answering Yes | | | | | | | | | |
| | Community Physicians | | | | | Total Physicians | | | | |
| | USA | | Russia | | P value | USA | | Russia | | P value |
| | N | (%) | N | (%) | | N | (%) | N | (%) | |
| Son/Daughter | 0 | (0) | 8 | (12) | 0.055 | 0 | (0) | 10 | (12) | 0.002 |
| Spouse | 30 | (97) | 45 | (65) | <.001 | 65 | (98) | 53 | (65) | <.001 |
| Sister/Brother | 0 | (0) | 1 | (1) | >.99 | 0 | (0) | 2 | (2) | 0.502 |
| Mother/Father | 0 | (0) | 6 | (9) | 0.173 | 0 | (0) | 10 | (12) | 0.002 |
| Lawyer | 0 | (0) | 8 | (12) | 0.055 | 0 | (0) | 8 | (10) | 0.009 |
| Other | 1 | (3) | 8 | (12) | 0.267 | 1 | (2) | 9 | (11) | 0.024 |

When does Physician Inform Patient of Terminal Illness?

| | Physicians Answering Yes | | | | | | | | | |
|--------------------------|--------------------------|------|--------|------|---------|------------------|------|--------|------|---------|
| | Community Physicians | | | | | Total Physicians | | | | |
| | USA | | Russia | | P value | USA | | Russia | | P value |
| | N | (%) | N | (%) | | N | (%) | N | (%) | |
| Always | 20 | (65) | 21 | (30) | 0.001 | 49 | (74) | 25 | (31) | <.001 |
| If Asked | 3 | (10) | 44 | (64) | <.001 | 6 | (9) | 52 | (64) | <.001 |
| Physician's Judgement | 7 | (23) | 4 | (6) | 0.032 | 10 | (15) | 4 | (5) | 0.048 |
| Patient no Right to Know | 0 | (0) | 0 | (0) | | 0 | (0) | 0 | (0) | |

Who Should Make End of Life Care Decisions?

| | Physicians Answering Yes | | | | | | | | | |
|---------------------|--------------------------|------|--------|------|---------|------------------|------|--------|------|---------|
| | Community Physicians | | | | | Total Physicians | | | | |
| | USA | | Russia | | P value | USA | | Russia | | P value |
| | N | (%) | N | (%) | | N | (%) | N | (%) | |
| Specialty Physician | 0 | (0) | 25 | (36) | <.001 | 1 | (2) | 28 | (35) | <.001 |
| Nurse | 0 | (0) | 0 | (0) | | 1 | (2) | 0 | (0) | 0.449 |
| Family Member | 4 | (13) | 4 | (6) | 0.249 | 7 | (11) | 6 | (7) | 0.497 |
| Patient | 29 | (94) | 9 | (13) | <.001 | 62 | (94) | 12 | (15) | <.001 |
| Family Physician | 1 | (3) | 39 | (57) | <.001 | 4 | (6) | 46 | (57) | <.001 |
| Other | 1 | (3) | 2 | (3) | >.99 | 4 | (6) | 3 | (4) | 0.701 |

Physician's Personal Choice of Care for Stage IV Pancreatic Cancer

| | Physicians Answering Yes | | | | | | | | | |
|-------------------------------------|--------------------------|------|--------|------|---------|------------------|------|--------|------|---------|
| | Community Physicians | | | | | Total Physicians | | | | |
| | USA | | Russia | | P value | USA | | Russia | | P value |
| | N | (%) | N | (%) | | N | (%) | N | (%) | |
| Intensive-Target Cure | 2 | (6) | 8 | (12) | 0.720 | 5 | (8) | 12 | (15) | 0.172 |
| Less Intensive - Target Progression | 6 | (19) | 9 | (13) | 0.414 | 13 | (20) | 14 | (17) | 0.707 |
| Supportive-Management | 21 | (68) | 52 | (75) | 0.427 | 38 | (58) | 57 | (70) | 0.107 |
| No treatment | 0 | (0) | 2 | (3) | >.99 | 2 | (3) | 2 | (2) | >.99 |
| Other * | 2 | (6) | 1 | (1) | 0.226 | 8 | (12) | 1 | (1) | 0.011 |

* discuss with oncologist, palliative care consult, discuss with family, depends on co-morbidities

physicians supporting this statement than Russian physicians 93% vs 64% $p=0.003$.

The open ended question on obstacles to providing end of life care solicited 74 responses from 31 Russian physicians and 44 comments from 29 US physicians. Russian respondents commented more on family issues of care (19 vs 11) and lack of resources (4,0 vs 6). US physicians commented more on communication issues (14 vs 4). US and Russian response numbers were similar on organizational (5 vs 4) and educational (8 vs 7) issues.

Discussion

This study shows the marked contrasting views on end of life care for physicians practicing in the United States and Russia. The US physicians, who work in an integrated palliative care health system, agree that patients should make their own end of life care decisions and should be informed about

their terminal prognoses. Russian physicians, who practice in a system with isolated palliative care provisions, felt that physicians should make decisions for their patients and prefer to inform their patients of terminal diagnoses only "if asked". These differences may highlight a paradigm practice difference in outlooks of patient autonomy and physician judgement. The results should be interpreted with consideration for each countries' cultural values of patients and the healthcare system traditions. Although not evaluated in this study, historically Russian patients rely heavily on physicians and relatives to guide their care, especially at the end of life. As a result, the answers of the physicians to our questionnaire likely reflect their patients' as well as their own cultural values rather than administrative and economic nuances of the healthcare system.

The practice of hiding a severe diagnosis from a patient in Russia dates back to the days of the USSR. "Perjury" to incurable and dying patients was the obligatory norm of Soviet



Table 4: Physician’s Comfort in Managing and Prescribing for End of Life Symptoms.

| | Managing | | | | | | | | | |
|----------------------------------|------------------------------|------|--------|-------|---------|------------------|------|--------|-------|---------|
| | Physicians Reporting Comfort | | | | | | | | | |
| | Community Physicians | | | | | Total Physicians | | | | |
| | USA | | Russia | | P value | USA | | Russia | | P value |
| N | (%) | N | (%) | | N | (%) | N | (%) | | |
| Pain | 27 | (87) | 69 | (100) | 0.008 | 58 | (88) | 81 | (100) | 0.001 |
| Agitation | 25 | (81) | 23 | (33) | <.001 | 54 | (82) | 28 | (35) | <.001 |
| Air Hunger | 24 | (77) | 22 | (32) | <.001 | 53 | (80) | 27 | (33) | <.001 |
| Inability to Eat/Drink | 23 | (74) | 16 | (23) | <.001 | 42 | (64) | 22 | (27) | <.001 |
| Increased Respiratory Secretions | 24 | (77) | 15 | (21) | <.001 | 54 | (82) | 20 | (25) | <.001 |

| | Prescribing | | | | | | | | | |
|------------------------|------------------------------|------|--------|------|---------|------------------|------|--------|------|---------|
| | Physicians Reporting Comfort | | | | | | | | | |
| | Community Physicians | | | | | Total Physicians | | | | |
| | USA | | Russia | | P value | USA | | Russia | | P value |
| N | (%) | N | (%) | | N | (%) | N | (%) | | |
| Opioids | 26 | (84) | 45 | (65) | 0.062 | 56 | (85) | 54 | (67) | 0.012 |
| Non-Narcotic Pain Meds | 27 | (87) | 46 | (67) | 0.050 | 62 | (94) | 53 | (65) | <.001 |
| Benzodiazepines | 25 | (81) | 16 | (23) | <.001 | 54 | (82) | 17 | (21) | <.001 |
| Antipsychotics | 19 | (61) | 11 | (16) | <.001 | 40 | (61) | 14 | (17) | <.001 |
| Non-Benzo Sedatives | 19 | (61) | 28 | (41) | 0.055 | 39 | (59) | 33 | (41) | 0.027 |

Table 5: Physician Practice Experiences with End of Life Care Over Last 6 Months.

| * | Community Physicians | | | | | | | | Total Physicians | | | | | | | | | |
|-----------------------------|----------------------|------|-----|------|--------|------|-----|------|------------------|-------|------|-----|------|--------|------|-----|------|---------|
| | USA | | | | Russia | | | | P value | USA | | | | Russia | | | | P value |
| | N/R/S | | O/A | | N/R/S | | O/A | | | N/R/S | | O/A | | N/R/S | | O/A | | |
| | N | (%) | N | (%) | N | (%) | N | (%) | N | (%) | N | (%) | N | (%) | N | (%) | N | (%) |
| Made Home Visit | 29 | (94) | 2 | (6) | 15 | (23) | 50 | (77) | <.001 | 62 | (94) | 4 | (6) | 21 | (27) | 56 | (73) | <.001 |
| Satisfied With Care | 4 | (13) | 26 | (87) | 41 | (62) | 25 | (38) | <.001 | 24 | (37) | 40 | (63) | 50 | (64) | 28 | (36) | 0.002 |
| Satisfied With Pain Control | 6 | (20) | 24 | (80) | 19 | (29) | 47 | (71) | 0.363 | 17 | (27) | 46 | (73) | 25 | (32) | 53 | (68) | 0.513 |
| Discussed Goals of Care | 12 | (41) | 17 | (59) | 19 | (29) | 47 | (71) | 0.228 | 24 | (37) | 40 | (63) | 22 | (28) | 56 | (72) | 0.239 |
| Patient Wishes Fulfilled | 5 | (17) | 25 | (83) | 23 | (35) | 43 | (65) | 0.069 | 22 | (34) | 42 | (66) | 28 | (36) | 50 | (64) | 0.850 |
| Patient Dies “with dignity” | 2 | (7) | 28 | (93) | 23 | (36) | 41 | (64) | 0.003 | 15 | (24) | 48 | (76) | 29 | (39) | 46 | (61) | 0.062 |
| Disclosed Poor Prognosis | 4 | (13) | 26 | (87) | 32 | (48) | 34 | (52) | 0.001 | 11 | (17) | 52 | (83) | 34 | (44) | 44 | (56) | <.001 |

* N/R/S = Never/Rarely/Sometimes
O/A = Often/Always

medicine [8]. Health care providers were incentivized strongly to act in this fashion. Doctors attempted to avoid anxiety in patients, as it was commonly believed that physical and emotional conditions are intimately related. In addition, it was believed that patients are incapable of making decisions and fully understand the consequences of their decisions regarding further treatment [8]. Only doctors could make such decisions, and treatment was performed “irrespective of the outcome”, while ignoring potential opposition from the patients [8].

In 2011, The Federal Law of Russian Federation “On the basis of the protection of public health in the Russian Federation” declared that everyone has the right to receive, in an accessible form, information about results of medical examinations, the presence of diseases, the diagnosis and the prognosis for the development of a disease [9]. However, according to statistics produced by the charity “Miloserdie”, doctors prefer to first give the news to relatives, and only then decide whether or not to inform the patient of the condition and prognosis. Nevertheless, a survey conducted by the charity “Live Now” and the website “Miloserdie.ru” found that 80% of patients would like to know their diagnosis first and only 2.6% of the survey participants agreed that their relatives be aware of their illness before them [10].

There were many detected differences in physician reported comfort with medication prescribing and symptom management at the end of life. All Russian respondents answered that they felt most comfortable managing pain, compared to 88% of US respondents. However, US respondents rated significantly higher comfort with prescribing all other listed medication classes compared to the Russian group. After closer analyses of these findings, it was determined that due to the necessary wording of the Russian questionnaire, Russian physicians interpreted the questions about symptom management as which symptom they were “most comfortable” managing. The US physicians were asked to select all symptoms they were comfortable managing. Another reason for the 100% Russian physicians’ comfort with pain management may be due to the fact that many of the Russian respondents had recently completed an educational program for the management of pain in palliative care. Therefore these findings must be interpreted with caution.

The open response question on obstacles to care found that while Russian care providers lament resource issues in end of life care settings, US providers felt that issues with communications were their greatest challenge. One issue raised by US respondents was conflict in goals of care and advanced



directive planning, which did not appear in any of the Russian comments. This may be related to the more paternalistic approach to decision making in Russia. Nine Russian comments mentioned limited availability of opioid pain relievers as an issue in end of life care; whereas no US respondents shared this concern. These findings are consistent with the differing healthcare systems in which the physicians are practicing. Issues of communication difficulties with patients and families, poor organization and lack of local resources for palliative care are all reported in other countries [11,12,3].

There is rare published cross-cultural research on end of life care. A small study comparing attitudes among generalists and specialists in Cambridge, UK and Kerala, India showed most attitudes were similar between both locations yet Indian clinicians placed more importance on their own views in their end of life care decision making [13].

This is similar to the Russian physicians' approach to these decisions. This may reflect a more paternalistic medical culture in India and Russia compared to the UK and the United States. This paternalistic approach is also emphasized in the present study with 57% of the Russian physicians believing that the family physician should make the end of life decisions and only 13% reporting that the patient should.

A 2015 study of physicians' attitudes on patient autonomy in East-Asian countries showed that 41% and 49% of Korean and Taiwanese physicians, respectively, agreed that the family should be told first about patients' serious medical conditions whereas only 7% of Japanese physicians agreed [14]. A 2010 study of primary care physicians in the United States and Hungary found that the majority of US physicians believed that patients had a right to know their terminal diagnosis [3]. The Hungarian physicians (44%) thought that the patient's right to know should be balanced by the physician's judgement of the patient's best interest and 40% disclosed the diagnosis only if asked. This finding is similar to the present study with 74% of US physicians always disclosing terminal illness versus 31% of the Russian physicians and 64% of the Russian physicians only disclosed diagnosis if asked.

Overall, there are some significant demographic differences in the compared groups that may influence the interpretation of the data. Most notably, the US sample included significantly higher proportion of academic and resident physicians relative to community physicians when compared to the Russian sample. We attempted to better control for the differences in percent of community physicians by reporting separate findings for the community physician groups. Only a small number of compared responses changed significantly when the groups were matched to compare only community to community physicians. Analyses were also controlled for gender differences. Further stratifying resident, academic and community groups

with larger sample sizes would help determine if differences in this study are related to a combination of variations in end of life training, cultural values, availability of resources for care or the uniqueness of our convenience sample.

There were many significant differences in attitudes and practices between the Russian and US primary care physicians in this study. While a handful of other studies comparing practicing groups across settings exist, much more investigation is needed ahead of a growing need for quality end of life care in an aging world. Cultural differences play a key role in end of life care and must be considered by all physicians caring for their dying patients.

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