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ORIGINAL ARTICLE

CONTENTS

Assessment of society's readiness for the legalization of euthanasia, carried out in the field of palliative medicine

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ABSTRACT

Aim: To determine the signs of society's readiness to legalize euthanasia for palliative patients by interviewing both the patients themselves and their relatives (caregivers) and specialists who provide medical, psychological, social and spiritual services at the end-of-life.

Materials and Methods: The study was carried out using a sociological method among palliative patients of three regions of Ukraine (Lviv, Kyiv and Kharkiv) on a random sample of 377 people surveyed during 2022–2024. The conducted research confirmed and clarified the previous results with greater reliability.

Results: Among the interviewed palliative patients, 60,0% complained of unbearable chronic pain; 69.4% thought about suicide at least once or tried to commit it. At the same time, only 40.3% thought about the possibility of euthanasia (or looked for ways to perform it) (1,7 times less). The prevalence of opinions about the possibility of euthanasia was higher among relatives (caregivers) of palliative patients (47,4%), and lower among those who provide services (30,1%). Among all respondents, suicide was discussed more often than euthanasia 1,5 times more often. And a broad social dialogue on the legalization of euthanasia is considered possible only by a little more than half of the respondents.

Conclusions: Ukrainian society is not ready for a broad dialogue about the need to legalize euthanasia, which actually means the continuation of the suffering of a significant number of palliative patients who do not receive adequate pain relief and most do not have the financial opportunity to use euthanasia tourism.

KEY WORDS: palliative and hospice care, chronic pain, suicide, questionnaires

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INTRODUCTION

The organization of palliative and hospice care in the country and integration of this system into the general health care system, reflect the country's ability to care for vulnerable segments of the population, to be a "social" state, to fulfill the declarative promises of its Constitution and other laws. Within the limits of the right to life, states independently decide what freedoms should be granted to their citizens regarding the disposition of their life, health, and death. The most controversial in all societies are the rights to abortion and euthanasia.

"Euthanasia" (from Greek εu – good, θάνατος – death) as an easy painless death, without torment and suffering is an alternative to dying with unbearable chronic pain caused by an incurable disease in countries such as Sweden, the Netherlands, Belgium, Switzerland, Finland, Germany, Spain, Luxembourg, Chile, Canada, 20 US states. Perception or rejection of ideas about the possibility of legalizing euthanasia in these countries took place with the participation of terminally ill patients, their relatives (family members, guardians, caregivers), people who, in their official duties or volunteer (public) activities, often come into contact with patients who die in pain and ask to take their lives. But even doctors, who are more often faced with difficult patients and their pleas for relief from suffering, are often not ready to perform euthanasia due to religious beliefs and ethical guidelines of medical universities [1]. The vast majority of low-income countries are unable to provide palliative care for patients at a sufficient level, so euthanasia can be offered as an alternative to dying in pain. Refusing to consent to such a voluntary medical procedure should not violate the right of palliative patients to die with dignity in their own country.

The most important argument for speeding up the euthanasia legalization is always the insufficient

Table 1. Distribution by age, gender and religiosity of patients interviewed at the second stage of the study, their caregivers and persons providing services to patients

Questionnaire questions and answers		Interviewees' categories						Total in three categories	
		patients		caregivers		services' providers			
		abs.	%	abs.	%	abs.	%	abs.	%
Sex	male	65	48,5	21	21,7	58	39,7	144	38,2
	female	69	51,5	76	78,3	88	60,3	233	61,8
	total	134	100,0	97*	100,0	146*	100,0	377	100,0
Age	adults	103*	76,9	-	-	-	-	-	-
	children	31	23,1	-	-	-	-	-	-
Religious	yes	35	33,9	37	38,1	82	56,2	154	44,5
	no	68	66,1	60	61,9	64	43,8	192	55,5
	total	103*	100,0*	-	-	-	-	346	100,0

Note: * – The answer, whether the respondent is a believer, was calculated only for adults.

Table 2. Distribution of surveyed patients (adults and children) by main palliative diagnosis

Category of diseases	Diseases of adults (with ICD-10 codes)	Diseases of children (with ICD-10 codes)	Number, persons (%)
- oncological diseases	malignant neoplasms (C00–C97, D00–D48)		35 (26,1)
- neurological diseases	dementia (F00–F03); epilepsy (G40–G47); multiple sclerosis (G35)	severe perinatal conditions (Q00–Q99); infantile cerebral palsy (G80); mental retardation (severe and profound) (F72–F79); Inflammatory diseases of the central nervous system (G00, G03, G04, G06, G08, G09);	57 (42,5)
- cardiovascular diseases	(I00–I99)		9 (6,7)
- infectious diseases	tuberculosis (A15–A19); HIV/AIDS (B20–B24)		11 (8,2)
- endocrine diseases	diabetes (E10–E14)		2 (1,5)
- arthropathy	rheumatoid arthritis (M05–M06)	-	2 (1,5)
- kidney disease	(N00–N15, N20–N23)	-	1 (0,8)
- liver disease	liver fibrosis and cirrhosis (K74)	chronic hepatitis (K73, K75.2, K75.3)	3 (2,2)
- lung disease	COPD (J43–J47)	-	1 (0,8)
- congenital malformations	-	(Q00–Q99)	7 (5,2)
- orphan diseases	-	phenylketonuria (E70.0); cystic fibrosis (E84); mucopolysaccharidoses (E76)	6 (4,5)
Total, persons (%)	103 (76,9)	31 (23,1)	134 (100,0)

Notes: CNS – central nervous system;
COPD – chronic obstructive pulmonary disease;
HIV/AIDS – human immunodeficiency virus/acquired immunodeficiency syndrome;
ICD-10 – International Classification of Diseases of the 10th revision [7].

analgesia of severe patients, which is one of the main needs of palliative patients [2]. The quality of pain relief for the majority of such patients has a strong influence on the ranking of countries according to the Quality of Death Index. In this ranking, most of the countries with the best quality of death are countries with a high level of income. But there is also an exception to this rule: in the "A" list, which includes the best countries, there is Uganda (31st place), which belongs to low-income countries. And, on the contrary, the Czech Republic (66th place) and Portugal (75th place) with high levels of profit are classified as the "worst" countries [3].

The integral assessment of the Quality of Death Index takes into account 20 indicators, combined into 5 cat-

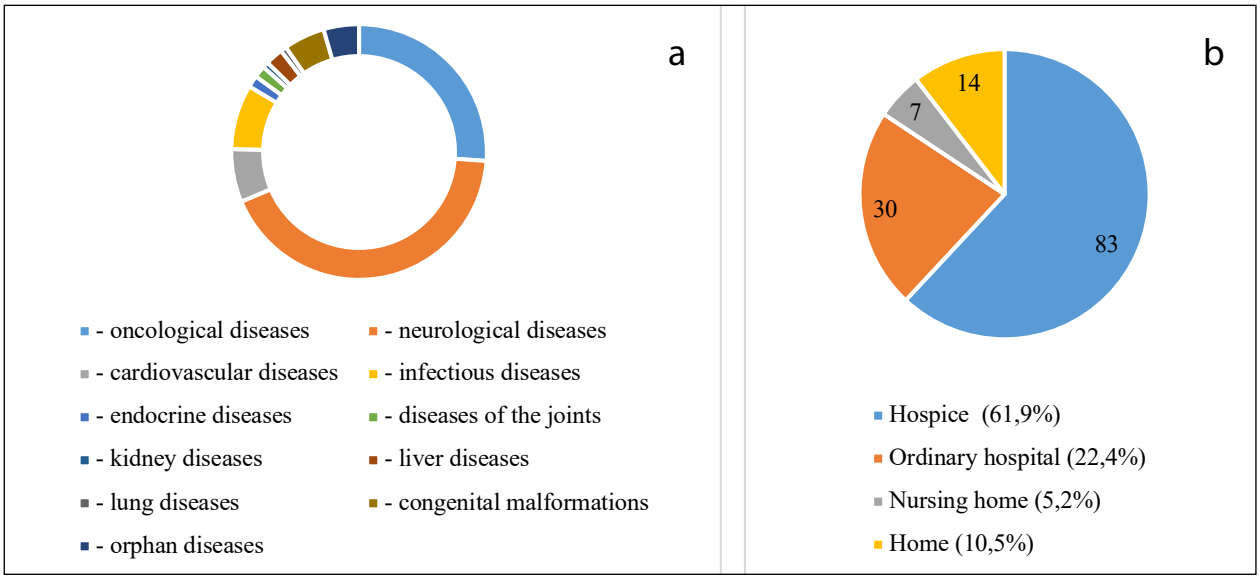

Fig. 1. Distribution of interviewed palliative patients: a) by diagnosis; b) at the place of treatment.

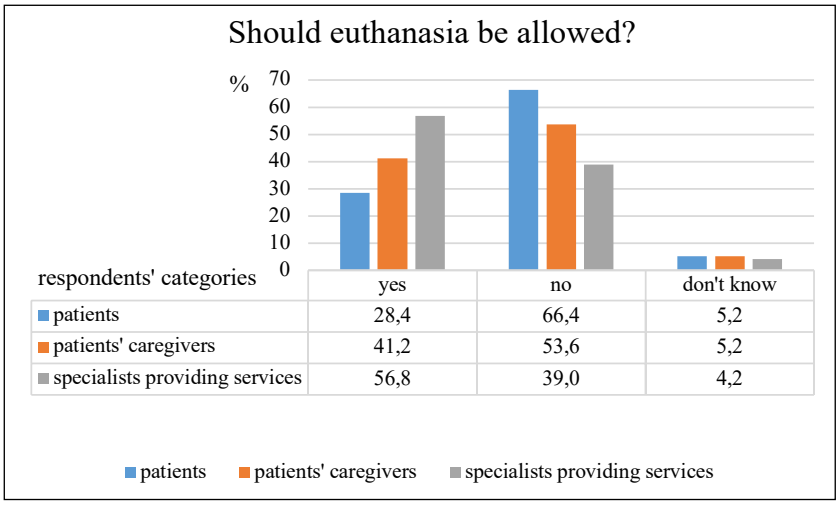

Fig. 2. The result of patients' survey, their caregivers and services' providers, at the second stage of the study regarding the need to legalize euthanasia.

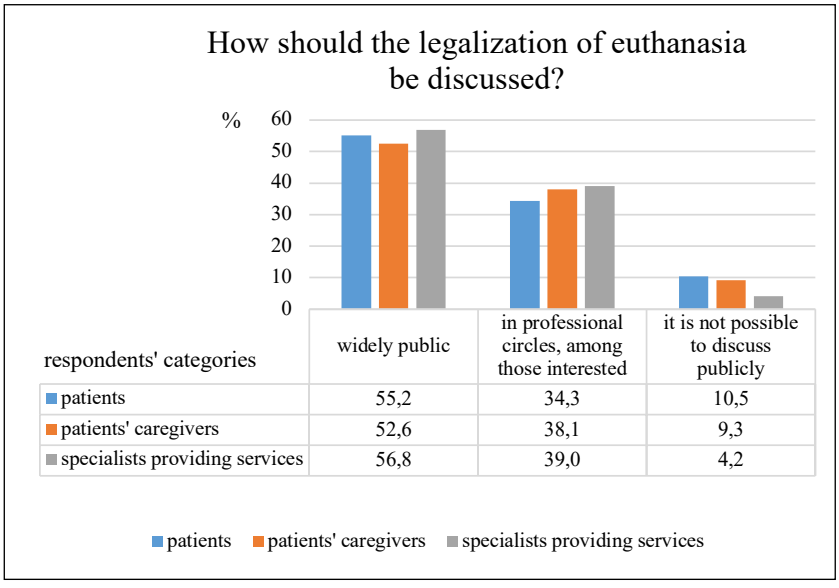

Fig. 3. The result of patients' survey, their caregivers and services' providers, at the second stage of the study regarding the possible format of the public debate on the euthanasia legalization.

Table 3. Findings from a survey of patients, caregivers and patient care providers in the second phase of a study on opinions about end-of-life patients' suffering by suicide or euthanasia

Questionnaire questions and answers		Interviewees' categories						Total in three categories	
		patients		caregivers		services' providers			
		abs.	%	abs.	%	abs.	%	abs.	%
The patient's thoughts about suicide / suicide attempt	yes	93	69,4	34	35,1	88	60,3	215	57,0
	no	20	14,9	63	64,9	58	39,7	141	37,4
	not answer	21	15,7	-	-	-	-	21	5,6
Total		134	100,0	97	100,0	146	100,0	377	100,0
The patient's thoughts about the euthanasia / search for the possibility	yes	54	40,3	46	47,4	44	30,1	144	38,2
	no	66	49,3	51	52,6	102	69,9	219	58,1
	not answer	14	10,4	-	-	-	-	14	3,7

egories. Among the categories, the quality of medical care has the greatest qualitative weight (30%). Three categories (human resources of the system of medical care and social provision; accessibility of medical care for the population; and direct adequacy to the needs of the organization of palliative and hospice care) have an impact on the final assessment in the amount of 20% each. Another 10% depend on community involvement [4]. The last fact shows the insignificant influence of public opinion on palliative medicine as a whole. Therefore, in order to determine the readiness of society to discuss the need to legalize euthanasia, it is necessary to study the opinion of patients, their relatives, and persons who provide services (treatment and support) to such palliative patients and their relatives.

AIM

To determine the signs of society's readiness to legalize euthanasia for palliative patients by interviewing both the patients themselves and their relatives (caregivers) and specialists who provide medical, psychological, social and spiritual services at the end-of-life.

MATERIALS AND METHODS

The research was conducted in 2022–2024 in hospices and palliative care units in three regions of Ukraine, namely Kharkiv (east of the country), Kyiv (center of the country) and Lviv (west of the country) using a sociological method: using a specially developed anonymous questionnaire [5]. 589 people were interviewed, from which 377 were randomly selected (the critical value of the standard normal distribution for the 95% confidence level was approximately 1,96). The responses of 377 adults were taken into account, 31 of whom responded on behalf of their minor child with a palliative diagnosis (parents or guardians, each adult on behalf of one child). The other 346 responses counted were on their own behalf. The respondents were divided into three groups (134 palliative patients, including 103 adults and 31 children, whose answers were obtained through parents; 97 caregivers of palliative patients; 146 specialists who provide medical, psychological, social and spiritual services to palliative patients at the end-of-life, and namely doctors, nurses, social workers, priests, volunteers), which is shown in Table 1.

At the previous stage of the research (2022–2023) [6], 284 people were interviewed, of whom 100 respondents were selected by customization with quota subgroups (10 subgroups of 10 people each). The survey result had a reliability level of $p<0,05$ for the entire group (100 people), but $p>0,05$ for each of the subgroups, which became one of the reasons for continuing the survey and increasing the sample. Separate data from the first and second stages of the study were compared.

At the second, current stage, the groups were enlarged (3 instead of 10). The data obtained from the respondents in the first stage in the city of Vinnytsia were not taken into account in the second stage. The answers of 59.0% of the respondents, included in the groups of the first stage of the study, were also taken into account when calculating the results of the second stage. The study of this stage covered an additional period (2024). Generalization of the diagnoses of palliative patients was carried out according to the same principles in the first and second stages of the study. The diagnoses of the second stage of the study are shown in Table 2 and Fig. 1.a, and the distribution of patients by place of treatment is shown in Fig. 1.b.

The questionnaire data were automatically transferred to the associated Google Forms file. Sample customization and randomization were performed using the "Randomizer & Calculator" application ver.

1.3.0/2023 (Antika Inc., Turkey). Randomized results were reported to Excel 2019 (Microsoft, USA) for final statistical processing. The result of calculations expressed as a percentage was rounded to the nearest tenth.

RESULTS

The most important result of the study is the ratio of answers to questions about thoughts or suicide attempts, thoughts or search for a way of euthanasia, the opinion about the need to legalize euthanasia and the feeling of constant unbearable pain caused by a palliative disease (for patients and their relatives who state complaints of constant pain), which presented in Table 3. Refusal to answer questions about suicidal thoughts or attempted suicide, as well as about possible euthanasia or finding a way to perform it, was accepted only from palliative patients. Their loved ones (caregivers) and persons providing services (treatment and support) to palliative patients were asked to answer these questions with a yes or no. The results of the survey of all categories of respondents about the need for legalization of euthanasia and the possible format of the discussion about such legalization are shown in Fig. 2 and Fig. 3. 75 out of 134 (60,0%) surveyed patients complained of unbearable chronic pain.

Attention is drawn to the greater prevalence of opinions about the possibility of euthanasia among relatives (guardians) of palliative patients than among the patients themselves. At the same time, palliative patients report their thoughts about the suicide of their loved ones only in about half of the cases.

DISCUSSION

It should be noted that our previous studies established the need to expand the list of palliative diseases for adults and children [8], in accordance with the WHO recommendation and the development of the Ukrainian Center for Public Data (2018). An expanded list of diseases will allow not only to treat more patients with serious diseases at the end of their lives as palliative, with appropriate state funding, but also bring palliative patients closer to the possibility of euthanasia instead of suicidal thoughts or attempts.

Today, chronic excruciating pain unfortunately prompts palliative patients more often to thoughts of suicide than to thoughts of euthanasia. The distribution of the interviewees into 3 approximately equal groups by region of the country, gender (48,5% of male to 51,5% of female) allows us to claim that the place of residence and gender had no influence on the average result. An important fact established by the study is that 60% of palliative patients experienced chronic unbearable pain, 69,4% thought about suicide at least once in their life, but only 40,3% of patients thought about performing euthanasia (or sought such an opportunity) (1,7 times less than suicidal thoughts). In our opinion, this indicates a misunderstanding of the procedure by a large part of patients. At the same time, the procedure of suicide tourism is not available for the majority of palliative patients of Ukraine, considering the high cost of euthanasia in Switzerland, which is the closest country to Ukraine, where you can get a similar service. Similarly, the proximity of Mexico, which has legalized euthanasia, is an option for US residents [9].

Seeking medically assisted end of life results in significantly less stigma than suicide attempts, as indicated by Eilers J.J. & Kasten E. (2022) [10]. Carrying out a legal, state-controlled euthanasia procedure entails less risk of lengthy criminal investigations for the loved ones of the deceased. In addition, the development of the euthanasia system, providing patients with an alternative to a dignified end of life in conditions of ineffective treatment, and especially analgesia, increases the assessment of the development of the entire system of palliative and hospice care [11–15].

CONCLUSIONS

The creation of a civilized system of euthanasia for the hopelessly ill with chronic excruciating pain that cannot be treated is an opportunity to realize the right of every person to a dignified death. The existence of such a right for everyone does not deprive believers of the right to refuse not to resort to euthanasia. Ukrainian society is not ready for a broad dialogue about the need to legalize euthanasia, which actually means the continuation of the suffering of a significant number of palliative patients who do not receive adequate pain relief, and most of them do not have the financial opportunity to use euthanasia tourism. The fact that severe palliative patients are more likely to think about suicide than about euthanasia indicates a lack of quality information about the procedure of medically assisted end of life.

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Due to the anonymous nature of the questionnaire, informed consent to participate in the study was not obtained. The general design of the study was approved by the Bioethics Commission of the Kharkiv National Medical University in 2022 (Protocol No.1).

The study was carried out within the scope of the topic "Medical and social justification of the improvement of the system of palliative and hospice care in Ukraine in the context of reforming the health care system", in accordance with the subject of the research work of the Department of Public Health and Health Care Management of the Kharkiv National Medical University 0124U002696 (2024–2026).

CONFLICT OF INTEREST

The Authors declare no conflict of interest

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