

Some issues in the seriously ill patients.

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Abstract

The modern situation requires the optimal organization and development of efficient and accessible of palliative care that most adequately meets the requirements and adequate quality of life of palliative patients and their families. Every year in Ukraine more than 500 thousand incurable patients and more than a million members of their families need palliative care, which determines the great socio-economic and humanitarian significance of this problem.

Methods: 146 severely diseased patients were interviewed. The results of research were mainly categorical data. Within the last year 56% of respondents were hospitalized four or more times. The part of admissions to hospital by the reference of a physician was only 49.4±4.0% and 20.5±3.2% of patients was admitted to hospital by the ambulance.

Conclusion: it was established a high multiplicity of using inpatient care by palliative patients. It was shown the necessity of development of the standards of palliative care for patients and their families at the level of primary medical care. Should take into account the successful project Leonardo experience (Ciccone MM) to solve this task.

Keywords: Need of palliative care, Patients with seriously illnesses, Inpatient treatment, Care coordination, Development of the standards of palliative care.

Introduction

The modern situation requires the optimal organization and development of modern efficient and accessible of palliative care (PC) that most adequately meets the requirements and adequate quality of life of palliative patients and their families, contributes to the preservation of human dignity at the end of life. [1]. According to foreign and national epidemiological studies, despite the specifics of the course of concrete diseases, patients in the final period of life have a complex of symptoms and disorders become common to different nosologies [2,3]. In addition to physical symptoms, for the majority (about 60%) of severely ill and incurable patients characterized by manifestations of acute psychological crisis: frustration, anger, anxiety, severe depression and fear, etc., which may deepen as a result of social isolation, stigma and material hardship [1,4]. National experts note that every year in Ukraine more than 500 thousand incurable patients and more than a million members of their families need PC of varying degrees of intensity, which determines the great socio-economic and humanitarian significance of this problem [5]. However, world experts have faced the same problem already. Ciccone MM showed that the strong cooperative and collaborative “team” creation (consisting of physicians, care managers, specialists and patients) improved patient health outcomes and promoted appropriate resource utilization on examples of 1160 patients living with seriously chronic illnesses.

Objective

To study the opinion of the severely ill patients regarding some aspects of providing palliative care.

Materials and Methods

The survey has been performed by interviewing 146 severely diseased patients at different in-patient health care facilities in Ivano-Frankivsk and 56 participants of post-graduate palliative care training program. The results of research were mainly categorical (qualitative) data. Therefore, calculation of each factor rates per 100 respondents, standard errors of rates, and Chi-Square Test (χ^2) for comparing group` differences have been used for statistical data analysis [6].

Results and Discussion

The majority of respondents lived in the city (69.9% vs. 30.1% rural population) and equal proportions of females and males have been found – 51.3% and 48.7% respectively. Age distribution of male and female patients among urban and rural population did not differ ($p>0.05$). However, in particular it draws attention to the fact that majority (65%) of interviewed incurable patients were working age people. Some of scientists also have marked this and negatively have emphasized socio-economic aspect of the problem [7,8].

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It is important to note that severe chronic diseases usually last for a long time. Thus; most of respondents (66.4±4.0%) mentioned they have been ill for several years. Mostly, these were hospice patients (80.0%), 70.2% Cancer Center and 67.4% Central City Hospital (CCH) patients compared to AIDS centre patients (29.4%, p<0.01). In addition, the long history of illness of the patients, in our opinion, makes their answers worth to trust.

Another aspect of the problem of severely ill patients is that they usually need in-patient treatment. Some questions of the organization of hospitalization of such patients are reflected in the scientific articles [9-11]. The results of our study showed that only 44.0% of the respondents were hospitalized once within the last year. The rest ones much more often, including one in ten (10.6%) four or more times.

We have analysed the ways of hospitalization and it was found that the part of admissions to hospital by the reference of a physician is quite low only 49.4±4.0%. At the same time slightly better looking this value in highly specialized medical settings, where it is 1.5-2 times higher than in Hospice and in CCH (p<0.01). Every fifth respondent (20.5±3.2%) was admitted to the hospital by the ambulance. Such a high share, especially in Hospice (32.3%) and in CCH (24.5%), is unlikely to be caused by really emergency conditions, because chronic patients, most of whom, as it was shown above, have a long history of illness. Most likely, ambulance was used to transport these, often lying, patients. Thus, Handley NR and others [12] also have indicated that the usage of emergency medical care for severely ill patients is a large and growing burden for the healthcare system, even in such a highly developed country as the United States. And the authors have noted also that reduction of unplanned acute care is a major priority for clinical transformation in oncology. This, once again, proves the necessity of the reform of emergency medical care and the formation of separate teams (non-medical) for these needs [13]. Also stands out the high level of hospitalization by the appeals of patients (17.9±3.1%) and upon an initiative of their relatives (12.2±2.6%, and in Hospice in twice more often –25.8%). On the one hand, it indicates the specificity of the palliative patient and the participation of relatives in making decisions about such patients. On the other hand, general analysis of hospital admissions shows inadequate cooperation, discoordination between different levels of health care providing and, above all, the organizational imperfection of the primary medical care that should define the patient's pathway and act as the coordinator of the providing medical

and non-medical needs both of the incurable patient and his family [14, 15]. As illustration, only fewer than half of the respondents were able to confirm, that their opinion was taken into account in case of choosing a medical facility for treatment (42.0±4.2%), physician (41.3±4.2%), possible place for care (31.9±4.0%) and methods of treatment (23.9±3.6%). Moreover, as can be seen from the data in Table 1, the level of deontological and legal needs of incurable patients is 2-6 times higher than the degree of their satisfaction. It is noteworthy that is important for the terminally ill patient, often lying, is a need to discuss issues about his disease (88.8±2.6%) and care organizations (88.2±2.7%). Ciccone M [20] notes - should consider the possibility of incorporating a patient empowerment model which considers the patient as the most important member of the health team. Karnik S and Kanekar A [16], Skelton L [17] also have showed the need to take into account the wishes of the patients regarding various aspects of the providing palliative care.

Our research has shown the thoughts of patients, who exactly have to provide different components of care for them. It was established that despite the well-known significant participation of relatives in the care [18,19], a fairly low percentage (17.6-44.7%) of incurable patients agreed with this (Table 2). Such responses can be a consequence of reluctance of patients to be a burden for their relatives and as a lack of competence of relatives in issues of care. Obviously, for the same reasons, the role of social workers (4.6-7.9%) and volunteers (11.1-17.1%) was evaluated even lower, as patients in inpatient settings probably did not meet with due to the lack of a multidisciplinary approach in the PC. In the same time, when patients answered the question about « should those who provide a care for patients receive appropriate training? », the absolute majority (94.2±1.9%) of the incurably ill patients were convinced of its necessity.

A multi-professional, post-graduate palliative care one-week training program was piloted in November 2019 at the University of Ivano-Frankivsk, Ukraine. The overall aim of this course was to promote the idea of timely integration of palliative care services, encourage networking and communication across the disciplines, enhance self-care, self-reflection, and team building awareness and skills. Participants (n=56) were recruited from hospitals, city clinics, hospices, palliative units and mobile home care teams including physicians, oncologists, psychologists, nurses, social workers and chaplains which directly working with patients.

Figure 1. The ratio between the level of deontological and legal matters of patients and the degree of their satisfaction by medical staff.

The need of explanation from the medical staff regarding	Level of needs (number of positive responses per 100 respondents)	Degree of satisfaction of needs (number of positive answers for 100 respondents)
Disease	88.8±2.6	59.2±4.1
Care opportunities	88.2±2.7	41.8±4.1
Complications and consequences of the disease	86.9±2.8	56.5±4.1
Their rights and responsibilities	86.8±2.8	41.8±4.1
Methods of treatment	85.4±2.9	42.8±4.1
Medical staff	82.6±3.2	29.5±3.8
Social services	82.1±3.2	19.2±3.3
Legal services	75.5±3.6	13.1±2.8

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Figure 2. Assessment by respondents the distribution of responsibilities for the care of incurable patients (per 100 respondents).

Components of the care of incurable patients	Doers					
	Relatives	Nurses	Junior nurses	Specially trained personnel	Social workers	Volunteers
Changing of clothes	44.7	33.6	48.0	19.1	5.9	16.4
Performing of physiological needs	29.6	25.0	59.2	20.4	7.2	11.2
Carrying out of hygienic procedures	27.0	30.3	58.6	22.4	4.6	11.2
Feeding	39.5	38.2	42.1	21.7	7.9	17.1
Lifting	30.3	27.6	53.9	23.7	6.6	13.8
Changing of bedclothes	17.6	30.7	66.0	17.6	5.9	11.1

A formal evaluation of this program was analysed. Some preliminary results turned out to be interesting. In terms of improving palliative care, participants were asked to focus on practical skills, especially in the psychological field, working with the family in times of grief and sorrow. Equally, participants were interested in teamwork, team communication, and especially in improving the collaboration between chaplains and psychologists. The most common wish was to repeat such courses all over Ukraine (15 times). All participants expressed the importance of multidisciplinary training in palliative care. Ciccone MM and others [20] also have stressed that ‘creating a strong cooperative and collaborative "team" consisting of physicians, care managers, specialists, and patients’ can ‘improve patient health outcomes and promote appropriate resource utilization’.

Conclusion

It was established a high multiplicity of using inpatient care by palliative patients.

The importance of improving the criteria and ways of hospitalization of seriously ill patients was shown, taking into account high rates of hospitalization among them by emergency medical aid and by self-referencing.

It was shown the necessity of development of the standards of palliative care for patients and their families at the level of primary medical care, with taking into account the wishes not only of medical professionals, but also patients (as a key person) and chaplains, psychologists and social workers who work directly with the palliative patient and his family members.

Should use the model Leonardo [20] to solve above issues in patients with seriously chronic illnesses. This project was feasible and highly effective in increasing patient health knowledge and had positive impact on the strong “partnership”.

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