Research Article

Severely Ill Patients: Some Issues of Palliative Care Organization

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Abstract
The objective of the research was to study the opinion of severely ill patients regarding some aspects of providing palliative care to determine the direction of its improvement.

Materials and methods. The sociological survey was performed by interviewing 146 severely ill patients treated in different in-patient health care facilities in Ivano-Frankivsk. The calculation of each factor rates per 100 respondents, the standard error of rates, and Chi-Square Test ($\chi^2$) for comparing group differences were used for statistical data analysis.

Results. Most respondents (66.4%) have been ill for several years. Throughout the year, every tenth patient (10.6%) was hospitalized more than four times. Only 49.4% of patients were admitted to the hospital with the referral from physicians. Every fifth respondent (20.5%) was delivered to the hospital by an ambulance, others (17.9%) - by self-referral. Fewer than half of respondents confirmed that their opinion was considered when choosing a medical facility (42.0%), physician (41.3%), place for care (31.9%) and methods of treatment (23.9%). The level of deontological and legal needs of incurably ill patients was found to be 2-6 times higher than the degree of their satisfaction.

Conclusions. High multiplicity of inpatient cases among palliative patients and the importance of improving the criteria and ways of their hospitalization were determined considering the high proportion of their hospitalization by emergency medical services and self-referral. The necessity of developing the standards of palliative care for patients and their families at the level of primary medical care was shown.

Keywords
palliative care organization

Problem statement and analysis of the recent research

Over the past decades, the ensuring of the maximum attainable quality of life for incurably ill has been a major humanitarian problem of modern society due to the adverse medical and demographic processes, including the population ageing and the increase in mortality rates from chronic non-communicable diseases. This requires the optimal organization and development of modern efficient and accessible palliative care (PC) system 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 specificity of the clinical course of specific diseases, the complex of symptoms and disorders in patients in the final period of their lives becomes common for various nosologies [2, 3]. In addition to physical symptoms, the majority (about 60%) of severely ill and incurably ill patients are characterized by manifestations of acute psychological crisis: frustration, anger, anxiety, severe depression and fear, etc., which may deepen due to social isolation, stigma and financial difficulties [1, 4].

Ukrainian experts note that every year in our country more than 500 thousand incurably ill 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 and places the task of developing this type of medical care on a par with the most relevant and important medical and social problems of our society [5].

The objective of the research was to study the opinion of severely ill patients regarding some aspects of providing palliative care to determine the direction of its improvement.

1. Materials and methods

The sociological survey was performed by interviewing 146 severely ill patients treated in different in-patient health care facilities in Ivano-Frankivsk: Ivano-Frankivsk Regional Clinical Palliative Care Centre (Hospice), Regional Cancer Centre (RCC), Ivano-Frankivsk Central City Clinical Hospital (CCCH) and Regional Centre for Prevention and Control of AIDS (AIDS Centre).

The results of the research were mainly categorical (qualitative) data. Therefore, calculation of each factor rates per 100 respondents, the standard error of rates, and Chi-Square Test
(χ²) for comparing group differences were used for statistical data analysis [6].

2. Results and discussion

The majority of respondents lived in the city (69.9% vs. 30.1% of rural population); there were equal proportions of females and males - 51.3% and 48.7%, respectively. Male and female patients residing in urban or rural areas did not differ by age (p>0.05). However, special attention should be drawn to the fact that the majority (65%) of interviewed incurably ill patients were of working age. Some scientists have marked this as well emphasizing the negative social and economic aspect of the problem [7, 8].

It should be noted that severe chronic diseases usually last for a long time. Thus, most respondents (66.4±4.0%) reported that they had been ill for several years. Mostly, these were hospice patients (80.0%), patients treated in RCC (70.2%) and Ivano-Frankivsk CCCH (67.4%) as compared to patients treated in AIDS Centre (29.4%, p<0.01). In addition, long duration of illness, in our opinion, makes their answers trustworthy.

Another aspect of the problem encountered by severely ill patients is that they usually need in-patient treatment. Some questions of the organization of such patient hospitalization were investigated by Simon ST et al. (2016) [9], Nauck F et al. (non-medical) for these needs [13].

When analyzing the ways of hospitalization, it was found that the proportion of admissions to the hospital by the reference of a physician was quite low - 49.4±4.0% only. This indicator was somewhat better in highly specialized medical settings (RCC and AIDS Centre) - 1.5-2 times higher than that in Hospice and Ivano-Frankivsk CCCH (p<0.01). Every fifth patient (20.5±3.2%) was delivered to the hospital by the ambulance. Such a high proportion, especially in hospice (32.3%) and Ivano-Frankivsk CCCH (24.5%), was unlikely to be caused by an emergency, as they were mostly chronic patients with a long duration of illness. The ambulance was most likely used to transport these bedridden patients (Fig. 2).

Handley NR et al. (2018) [12] indicate that the use of emergency medical care by palliative patients is a large and growing burden for the healthcare system even in such a highly developed country as the United States. The authors note that the reduction in even unplanned acute care among such patients becomes the main priority for clinical changes in oncology. This, once again, proves the necessity of reforming national emergency medical care and forming separate teams (non-medical) for these needs [13].

More attention should be paid to high proportion of hospitalization of self-referred patients (17.9±3.1%) and hospitalization on a family’s behalf (12.2±2.6%, in hospice twice more often - 25.8%). On the one hand, it indicates the specificity of palliative patient and the involvement of family members in decision making for such patients. On the other hand, the cumulative analysis of hospital admissions shows an inadequate cooperation, discoordination between various levels of health care and, principally, the organizational imperfection of primary medical care that should determine the patient’s route and act as a coordinator for providing medical and non-medical needs to both incurably ill patients and their families [14, 15].

Only fewer than half of respondents were able to confirm, that their opinion was considered when choosing a medical facility for treatment (42.0±4.2%), a physician (41.3±4.2%), possible place for care (31.9±4.0%) and methods of treatment (23.9±3.6%).

Moreover, the level of deontological and legal needs of incurably ill patients was 2-6 times higher than the degree of their satisfaction (Table 1).

It is noteworthy that for an incurably ill patient, often bedridden one, the needs of discussing own illness (88.7±2.6%) and care organization (88.2±2.7%) were equally important. Karnik Set al. (2016) [16], Skelton L (2016) [17] indicated the need of considering the patients’ wishes regarding various aspects of providing palliative care.

We studied the patients’ opinion regarding who should provide care for them. Despite well-known significant involvement of relatives in the care [18, 19], a rather low percentage (17.6-44.7%) of incurably ill patients agreed with this statement (Table 2). Such responses may be due to the reluctance to be a burden for their relatives, as well as a lack of competence in issues of care.

Most patients (42.1-66.0%) considered junior medical staff as the main providers of services; 25.0-38.2% of patients indicated nursing staff (Table 2). It remains without saying that the patients’ answers were influenced by their wishes and their own experience, as the role of specially trained personnel, the number of which is, unfortunately, very low in our country, was rated rather low (17.6-23.7%). 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 in-patient settings probably did not meet them due to the lack of a multidisciplinary approach in PC.

At the same time, when patients answered the question “Should those who care for patients receive appropriate training?”, the absolute majority (94.2±1.9%) of incurably ill patients were convinced of its necessity. The importance of training for providing PC is constantly highlighted in the recommendations of international experts [19, 20].

3. Conclusions

1. There was determined a high multiplicity of inpatient cases among palliative patients.

2. There was established the importance of improving the criteria and ways of hospitalization of seriously ill pa-
Figure 1. Distribution of patients by the frequency of hospitalization throughout the year

Figure 2. Distribution of hospitalization ways among respondents
Table 1. Ratio between the level of deontological and legal needs of incurably ill patients and the degree of their satisfaction by medical staff

| Need for clarification by the medical staff regarding: | Level of needs (number of positive responses per 100 respondents) | Degree of satisfaction of needs (number of positive answers per 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                                                                      |

Table 2. Assessment of the distribution of responsibilities for the care of incurably ill patients by respondents (per 100 respondents)

| Components of the care of incurably ill patients | Relatives | Nursing staff | Junior medical staff | Specially trained personnel | Social workers | Volunteers |
|--------------------------------------------------|-----------|---------------|----------------------|-----------------------------|----------------|------------|
| Changing of clothes                              | 44.7      | 33.6          | 48.0                 | 19.1                        | 5.9            | 16.4       |
| Satisfaction 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 bed linen                            | 17.6      | 30.7          | 66.0                 | 17.6                        | 5.9            | 11.1       |

Patients considering the high proportion of their hospitalization by emergency medical services and self-referral.

3. The necessity of developing the standards of palliative care for patients and their families at the level of primary medical care was shown.

**Prospects for further research**

The development of measures to improve the provision of palliative care is promising.

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