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Medical and social peculiarities of incurable patients as objects of palliative and hospice care

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The sociological survey has been performed by interviewing 156 incurable and severely ill patients at different in-patient health care facilities in Ivano-Frankivsk (Western Ukraine). It was established that incurable diseases are accompanied with low level quality of life, mainly due to dissatisfaction of patients' health state, caused by the disease, financial destitution, limitation of social activity, and worsening of family relationships, feelings of uselessness to society, disappointment in life, loneliness and apathy to everything and so on. High level of distrust, lack of information and medical staff's attitude and its indifference to patients confirm insufficient medical staff knowledge in regards to communication with incurable patients. These items are necessary to consider in curriculums in palliative care for under and postgraduate medical education.

Keyword: Incurable Patients, Palliative and Hospice care.

1. Background

Currently an increasing burden of chronic incurable diseases is observed in Ukraine and worldwide that lead to development of severe clinical conditions and disorders of basic physical, psychological and social functions ^[3, 4, 5]. Such patients, in spite of their age, gender and specific diseases, suffer from various, frequently extremely painful, subjective maladies and serious functional disorders ^[1, 2, 4, 5]. According to foreign and national epidemiological research the complex of symptoms and disorders becomes similar in the end-of-life phase in different diseases (exhausting painful syndrome, severe asthenia, dysfunction of urinary bladder and bowels, lost ability to self-service) ^[1, 2, 4, 5].

Besides physical symptoms, severely diseased and incurable patients (about 60%) have signs of acute psychological crisis: despair, anger, grief, expressed depression and fear, etc. that can be

intensified as a result of social isolation, stigmatization and financial destitution ^[2, 4, 5].

Palliative and Hospice Care – is an approach, that can most completely solve all problems of incurable patients with limited life prognosis and their relatives ^[2, 3, 4, 5, 6].

According to the national experts, every year more than 500 thousand incurable patients in Ukraine need palliative and hospice care. This determines paramount social-economic and humanitarian importance of this problem in our society ^[7].

2. Aim of study

To examine medical and social features of incurable and severely diseased patients to define directions improving palliative and hospice care.

3. Materials and methods

The sociological survey has been performed by interviewing 156 incurable and severely diseased patients at different in-patient health care facilities in Ivano-Frankivsk (Western Ukraine): Regional clinical centre of palliative care (Hospice), Regional oncology hospital, Central clinical city hospital and Regional centre of AIDS prevention and control (hereinafter - AIDS centre).

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 analysis¹⁸.

4. Results and Discussion

Equal proportions of females and males (51.3% and 48.7% respectively) have been found among the interviewed patients. The majority of them

lived in the city (69.9% vs. 30.1% rural population) that determined significant differences of respondents' distribution between regional and city health care facilities ($p < 0.05$). However, only regional hospice patients equally represented urban and rural residents (51.6% and 48.4%). In other regional health care facilities urban population prevailed among interviewed incurable patients: 64.0% in oncology hospital and, especially, in the AIDS centre - 77.3%. To our mind, this indicates lower access to palliative care by rural population, and might reflect higher prevalence of HIV-infection in cities.

Age distribution of male and female patients among urban and rural population did not differ ($p > 0.05$). Moreover, as shown in Fig. 1, 65% of interviewed incurable patients are working age people that emphasize socio-economic aspect of the problem.

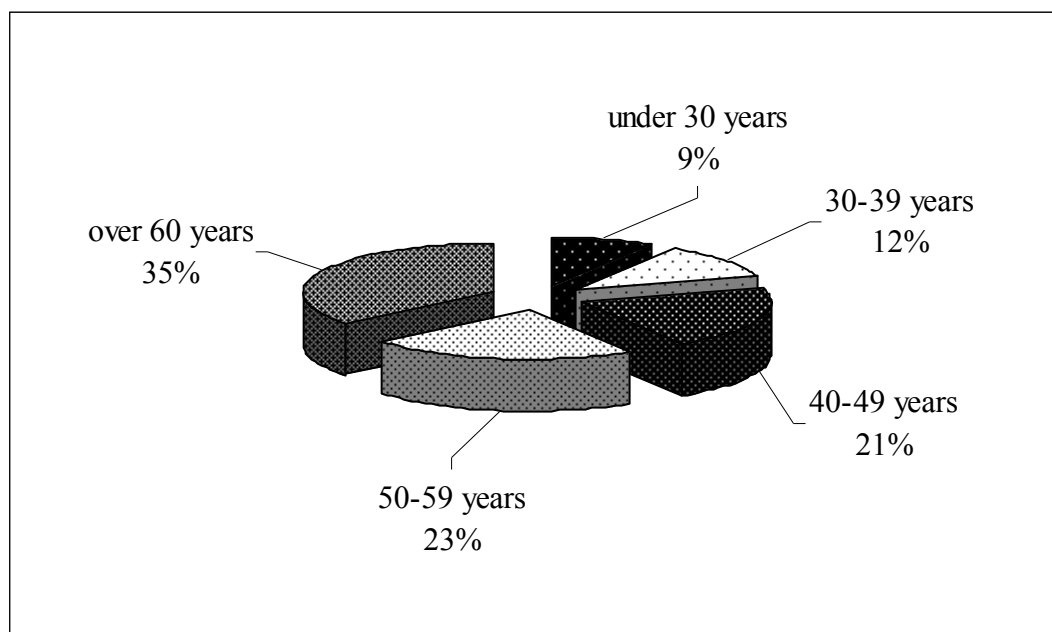


Fig 1: Age distribution of interviewed incurable patients

Age distribution of patients differed depending on the type of health care facilities ($p < 0.001$). The youngest patients were from AIDS centre: all 22 respondents were aged under 50 years old, 54.5% of them were young people under 30 years of age. 70% of interviewed patients of the regional

oncology hospital and half of patients of hospice (48.4%) and central city clinical hospital (52.4%) were the working age people.

Severe chronic diseases usually last for a long time. Most of respondents ($66.4 \pm 4.0\%$) mentioned they have been ill for several years.

Mostly, these were hospice patients (80.0%), 70.2% - regional oncology hospital and 67.4% - central city clinical hospital patients compared to AIDS centre patients (29.4%, $p < 0.01$).

The incurable diseases are a serious challenge for the patient and his /her family and for the health care system as well. Thus, half of the patients ($49.4 \pm 4.0\%$) assessed their health status as extremely unsatisfactory, the same part ($44.2 \pm 4.0\%$) – as satisfactory and only $6.4 \pm 2.0\%$ - as good. The most of respondents admitted that the disease significantly limited their social activity ($78.2 \pm 3.3\%$) and worsened the quality of their lives ($75.5 \pm 3.5\%$).

It's clear that presence of severe long-term chronic illness requires high financial expenses that considering general low level of income in our country puts additional financial burden not only for the state and municipal budgets, but also for the patients and their families. It is not surprising that in spite of their gender, place of residence and medical care ($p > 0.05$), only $9.0 \pm 2.3\%$ of the respondents considered themselves financially assured. Although the majority ($55.8 \pm 4.0\%$) classified themselves as people with average level of income, over one-third ($35.3 \pm 3.8\%$) - had serious financial problems becoming worse with age ($p < 0.05$).

Palliative patients require certain conditions for the organization of medical care not only in health care facilities but also at home. However, only $11.5 \pm 2.6\%$ of the respondents live in completely comfortable conditions, $67.9 \pm 3.7\%$ - have satisfactory living conditions, but one out of five ($20.5 \pm 3.2\%$) incurable patients regardless of their age, gender, place of residence and medical care complained of unsatisfactory living conditions.

Analysis of marital status showed that only half of incurable patients are married ($58.3 \pm 3.9\%$). The rest of them are single without a permanent life partner: widowed ($19.2 \pm 3.2\%$), divorced ($12.2 \pm 2.6\%$) or those who have never been married ($10.3 \pm 2.4\%$). Naturally, marital status

changes with the age ($p < 0.001$). Thus, the most significant part of single (71.4%) was observed among young patients and one-third (33.3%) of patients aged 30- 39 years old were divorced. The growth trend in marriage rates was typical for patients under 60 years ($28.6\% - 77.8\%$) and almost half of the respondents after 60 years (42.9%) were widowed.

It's known the system of palliative and hospice care in Ukraine is not formed yet, that's why family members of severely diseased patients play the central role in taking care after them. But, the fifth part ($20.5 \pm 3.2\%$) of severely ill or incurable patients lives alone.

The diagnosis of incurable disease in one of the family members often causes the tension in the family relationship. Thus, only the one-fifth ($23.1 \pm 3.4\%$) of interviewed patients described relationships in their families as friendly, others – $55.8 \pm 4.0\%$ characterized them as satisfactory and one in five of patients ($20.5 \pm 3.2\%$) - as unsatisfactory and conflicting. It should be noticed that a large proportion of the respondents ($22.1 \pm 3.4\%$) complained of deterioration in family relationships after diagnosis of their incurable disease, moreover the number of HIV-positive people among them was up to 40.0% ($p < 0.05$), that probably is related with stigmatization of such patients. On the other hand, the part of patients indicated improvement in family relations after diagnosing severe lesion, mostly these patients were central city clinical hospital and regional oncology hospital patients (25.0% and 20.4% vs. 0.0% of hospice patients and HIV- infected ($p < 0.05$).

Taking into account above-mentioned, it becomes clear why only $7.9 \pm 3.1\%$ respondents were completely satisfied with their present life in spite of their age, gender and place of residence ($p > 0.05$). The rest of them determined it as satisfactory ($53.2 \pm 4.0\%$) and one-third ($28.8 \pm 3.6\%$) – as unsatisfactory.

It was found that severe physical state of patients is often accompanied by feeling of their uselessness to society ($76.2 \pm 3.5\%$),

disappointment in life (73.5±3.5%), loneliness and apathy to everything (68.9±3.7%), isolation from public life (67.3±3.8%), feeling as burden for their families (55.6±4.0%).

Special concern is the fact that 71.5±3.7% of the respondents noted medical staff indifference to them. However, the most negative comments (100.0%) were expressed by HIV-infected patients, and the least – by hospice patients (38.7%, p<0.001).

Similar correlation demonstrated respondent's answers concerning their trust to medical staff. Only 14.8±2.9% of incurable patients completely

trusted medical personnel, next part (66.5±3.8%) - moderately, and one in five (18.7±3.1%) strongly expressed their lack of trust. Moreover, as shown in Fig. 2, the distribution of these values clearly depended on the type of health care facility (p<0.05).

Hospice patients expressed the highest level of trust to medical staff and patients of oncology hospital and AIDS centre - the lowest (Fig. 2). These data are disturbing because it is known that patients who don't trust the doctors demonstrate worse treatment results.

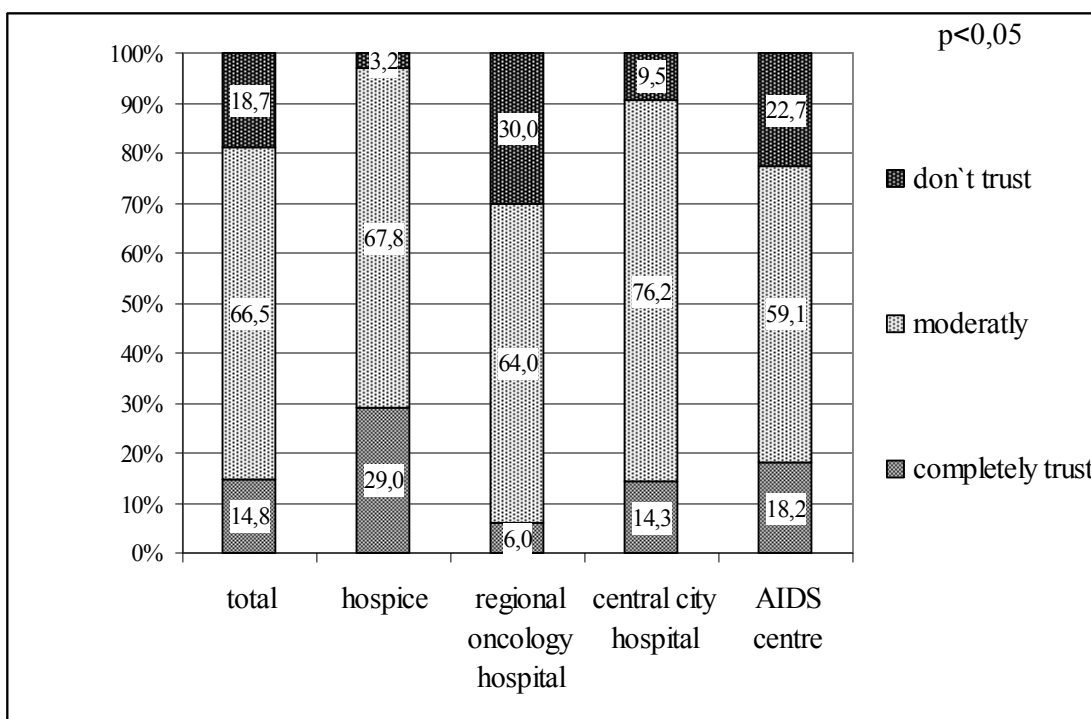


Fig 2: Levels of trust to medical staff among respondents according to health care facility type

On the other hand, the highest levels of trust with simultaneous lowest rate of complaints for the indifference of the hospice medical staff, to our mind, confirms the effectiveness of regular staff training related to specific character of communication with incurable patients.

Overall, the high number of patients who were unsatisfied with the attitude of medical staff towards them can be caused by outdated paternalistic model of communication "medical

employee-patient" which does not correspond to modern model of complete partnership and patient's participation in making clinical decisions towards them. As example, only less than half of respondents could confirm that their opinion was taken into account by choosing health facility for treatment (42.0±4.2%), attending doctor (41.3±4.2%), possible place of care (31.9±4.0%) and methods of treatment (23.9±3.6%).

It is known that the main task of palliative and hospice care is to provide the most possible highest level quality of life of incurable patient and his family, including their need for medical services. However, the answers of interviewed incurable patients pointed out high level of dissatisfaction with medical services.

As shown in Fig.3, the main complaints have economic origins. Most of incurable patients

were unsatisfied with the high cost of medicines (89.5±2.5%), low funding of health facilities (79.5±3.3%) and expensive medical services (76.5±3.5%). This is quite understandable, taking into account that long-term incurable disease often tires out both the patient and his/her family, and as it was shown, most incurable patients consider themselves poor.

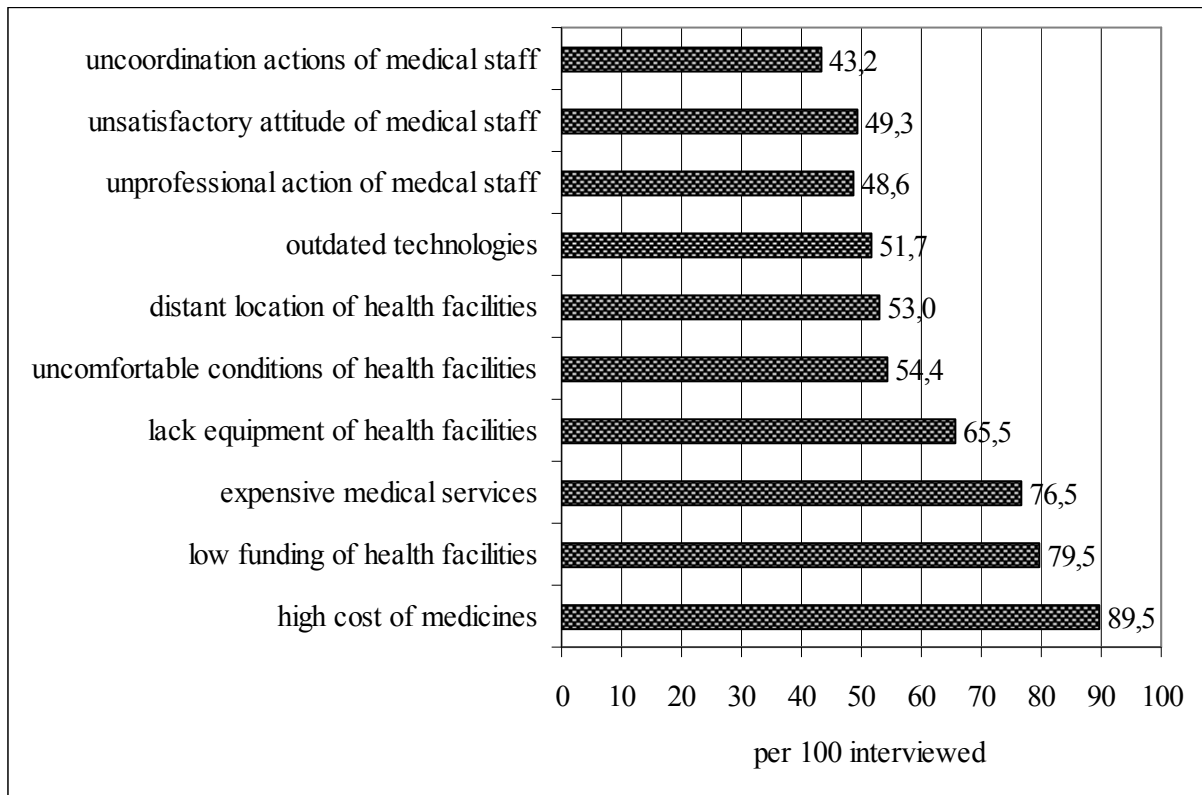


Fig 3: Reasons of interviewed patients' dissatisfaction by current state of palliative and hospice care provision.

The other significant complaints of respondents were focused on related with the previous structural and resource health care system problems. Thus, two-thirds of patients (65.5±3.9%) expressed their dissatisfaction with lack of equipment in health facilities, half of the respondents complained of the uncomfortable conditions (54.4±4.1%), distant location of health facilities (53.0±4.1%) and outdated technologies (51.7±4.1%).

Great contribution to dissatisfaction with medical care was caused by medical staff activity. Almost half of the respondents were indignant with

attitude to them (49.3±4.1%), unprofessional, to their mind, (48.6±4.1%) and uncoordinated (43.2±4.1%) actions of medical staff. Other complaints were not so considerable, mostly concerning improper quality of food (40.0±3.9%), nursing (21.2±3.3%), lack of emotional support from medical staff (19.9±3.2%) and so on.

5. Conclusions

1. It was established that incurable diseases are accompanied with low level quality of life, mainly due to dissatisfaction of patients'

health state, caused by the disease, financial destitution, limitation of social activity, and worsening of family relationships, feelings of uselessness to society, disappointment in life, loneliness and apathy to everything and so on.

2. High level of distrust, lack of information and medical staff's attitude and its indifference to patients confirm insufficient medical staff knowledge in regards to communication with incurable patients. These items are necessary to consider in curriculums in palliative care for under and postgraduate medical education.

Perspectives of further research will target development of measures to improve medical staff training during under and postgraduate education in the sphere of palliative and hospice care.

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