

PALLIATIVE CARE IN ARMENIA: CURRENT SITUATION AND PROBLEMS

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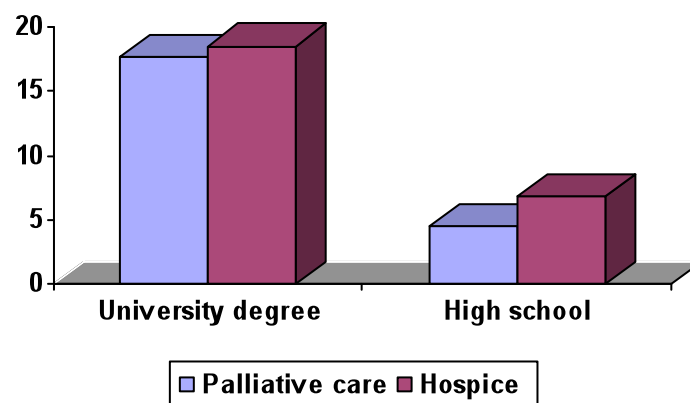
The Armenian economy including health care is in transition. The health care system was inherited from and still keeps up many regulations, traditions and mentality of the soviet period, a period with too much ideology and too little economic sense. Discussion of economic effectiveness of health care was not appropriate, when the subject is priceless – human health and life. Less expensive alternatives to hospital care institutions such as nursing houses, convalescent clinics and hospice did not exist. Although the Armenian health care system has been in the process of reform for twenty years, little has changed in palliative and hospice care. The “Law of the Republic of Armenia on Medical Care and Services to the Population” does not recognize palliative care and hospice care. Palliative care and hospice care are not included in the List of medical services and specialties approved legislatively by the Ministry of Health of the Republic of Armenia. There are no specialists in palliative care and no curriculum for their training in Armenia.

Palliative and hospice care are not included in our national basic benefits package, as there is no infrastructure for such care. If a patient were to arrange independently for palliative care it would be prohibitively expensive. As a result of absence of palliative care supply the demand for that service is completely hidden. This situation creates a false impression that there is no problem regarding palliative and hospice care. Meanwhile, annually in the republic 22-27 thousands of deaths are registered, including 3.5-5.2 thousands from cancer diseases and it is expected 70% of them would benefit from palliative care.

The problem of palliative care is especially urgent in pediatrics. The morbidity among children has increased significantly – in 1990 the incidence rate of childhood cancers was 17.5 per 100 000 and has risen to 42.8 in 2007. The

diabetes incidence rate has almost doubled in this period- from 4.4 per 100 000 to 8.0, and birth defects increased from 120.4 per 100 000 in 1995 to 209.2 in 2007. Regarding the cause specific mortality data among children, official statistics do not provide good data by age group. There are reasonable doubts about credibility of official statistics, and the real situation could be worse. In addition the demography of Armenia is in flux. During recent decades the birth rate fell from 25 per 1000 to 10-12 per 1000, total fertility rate is about 1.7(2005), the proportion of children aged 0-14 decreased from 30.5% in 1990 to 19% in 2008.

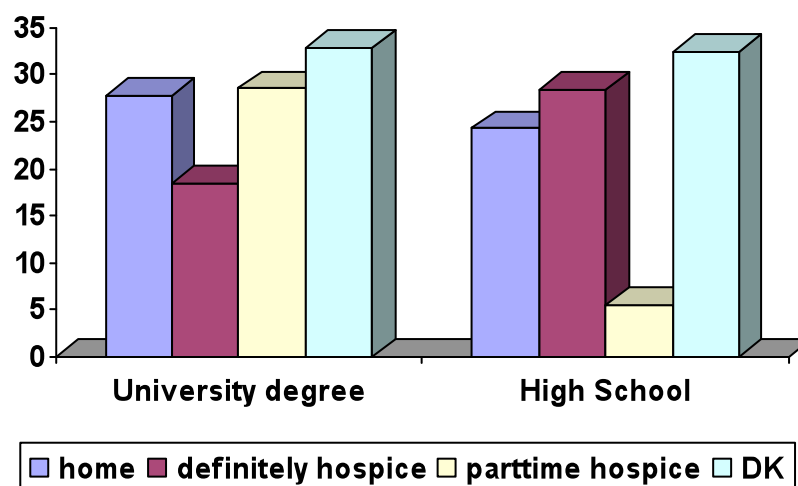
With the aim of identifying needs in children palliative care, parents' perception and understanding of this issue we conducted a survey of families. 193 respondents mainly from Yerevan, capital of Armenia, were interviewed. Although 29% reported the occurrence of need in palliative care in their families in the past, on average only 13% of respondents had heard about palliative care and 14% knew what hospice is. Among those with terminally ill family members 82.1% did not know about palliative care. There was statistically significant association in education level and awareness on palliative care, 17.6% of respondents with university degree vs. 5.4% with high school or college (chi-square 5.03, p=0.025).



Graph 1. Association of awareness on problem with education

University graduates were more likely to know about hospice than those only with high school education (18.5% vs. 6.8%, chi-square 4.29, p=0.038). After explanation, 68.4% of respondents expressed interest in receiving hospice care, 10.4% were not interested, and the rest were not sure.

Child and family wellbeing and comfort levels are crucial factors for making decisions on hospital or home care. Armenia there is a principle of absolute dominion of parents and heads of family. Similarly there is a paternalistic model of relations of physicians with patients. Such concepts as “patient oriented care”, “informed consent” are in their first steps. So we were interested to learn if parents are ready to provide children with hospice care or home care. A major consideration for hospice care is the family’s living conditions. Armenian families have on average 1.9 children per household and nation-wide, 75.5% of households have 2 or fewer rooms used for sleeping. There is a significant urban-rural disparity with nearly twice as many rural households having 3 or greater rooms used for sleeping as compared to urban homes, (33.5 vs. 18.5%). In our study less than 50% of families with siblings have separate children’s rooms. regardless, more bedrooms rooms was not associated with interest in keeping children at home or using hospice (30% and 25.6% respectively, chi-square 0.24, p=0.63). But still many people said that they would prefer hospice if there were another child at home. University graduates were more likely to consider living conditions while choosing hospice rather than those with school education, chi-square 7.92, p=0.048 (graph 2.)



Graph 2. Association of parent’s preferences about hospice care with their education (part time hospice – when there is another child in family).

Conclusion. There are several problems relating to palliative and hospice care in Armenia in legal, organizational, institutional areas and in public awareness and perception as well. Official authorities, professional health care associations, NGO and benevolent organizations should unite their efforts and contribute for establishment palliative and hospice care in Armenia. In our opinion, the first urgent step should be the legal regulation and institutional strengthening of this service, then the adoption of curriculum and training programs, education of physicians.

An advocacy campaign is needed to improve understanding and support of hospice care. The population often misapprehends hospice care as a way of getting rid of terminally ill person, to free family from severe burden and concerns. This is national cultural and traditional belief. Armenians have always had extended families of three – four generations living together and mutual support is an important part of the culture's moral values. To better evaluate needs in hospice care, a large scope study would be required.