

Palliative Care Services in Israel and Abroad

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1. Introduction

In recent decades, care of people at the end of life has become of central concern to health systems. Changes in the composition of the population – primarily its aging – and in morbidity – primarily the transition from care of acute illnesses to chronic ones, and the increase in cancer morbidity and mortality rates – have heightened the need to care for people whose deterioration is gradual and whose suffering is protracted. Health systems in the west have come to realize that palliative services are the most appropriate for patients at the end of life. Provided according to the modern hospice approach, palliative services aim to improve the quality of life of the dying, without extending their life unnecessarily. This is accomplished by controlling the physical symptoms of illness, such as pain; providing psychological, emotional, existential, and spiritual support; and considering the wishes of the patient and his family. While the belief that every individual has the right to palliative care at the end of life is gaining ground in Israel, it has yet to be widely accepted. The uniform benefits package mandated by the National Health Insurance Law, which dictates the services and medications the health plans are obligated to provide their members, does not currently include a detailed definition of services for the dying; neither have eligibility criteria for such services been determined. While the health plans do provide various services to patients who are dying, to date there has been no comprehensive overview of these.

The situation regarding palliative care services throughout the world shows sizeable differences among countries as to the extent of services. For example, there are two palliative care services per one million people in Israel, compared to 1.5 in Argentina and 0.5 in Jordan, while in England there are 13 per one million people, and in Scotland 25. In addition, there are substantial differences among countries regarding official recognition, sources of funding, baskets of services, training and other indices. The study provides a comprehensive and thorough picture of hospice and palliative services in Israel, examines their characteristics, work patterns, and quality, and identifies unmet needs.

2. Palliative Care Services in Israel's Health System

- ♦ **Acute hospitals:** There are three hospital-based hospices in Israel – in Jerusalem, Tel Aviv, and Haifa – which have been allotted a total of 76 beds, and which serve some 1,200 patients per year. In addition, in a few acute hospitals, palliative consultation services are offered, especially pain control. However, this service is not significantly visible; the staff of other hospital departments are often unaware it exists. Consequently, many of those who die in hospitals never receive the palliative care that could ameliorate their suffering at the end of life.
- ♦ **Long-term care institutions:** Although a large proportion of the residents of long-term care institutions suffer from multiple symptoms at the end of life, most of these institutions abide by conservative treatment methods, which consist primarily of medication to alleviate pain and other physical symptoms. A few geriatric hospitals and institutions have recently begun

implementing the modern hospice approach, by providing psychological and emotional support while treating physical symptoms.

- ◆ ***Home medical care units, and units for continuing medical care and monitoring:*** Israel's four health plans have about 100 units in all of their districts, which provide medical, nursing, and rehabilitative home care. These units treat housebound individuals, many of whom are elderly and/or suffer from a variety of chronic and functional disabilities; however, they do not focus on specific illnesses. The units treat between 3,000 and 4,000 patients per year with metastasized cancer who need palliative care. Some of these patients receive care directly from the staff of the home care unit, but most are treated by their family physician and community clinic, which avail themselves of the consultation, guidance, and support of the staff of a home-care unit. Most of these staff are available during working hours only; although some are on-call by telephone until evening, they are not physically available in the evening and at night.
- ◆ ***Oncology nurses in the community:*** Some of the home-medical care units have oncology nurses on staff, who care for dying patients in the community (always along with the patient's direct caregivers). However, for the most part, these nurses guide other community health care providers in coping with situations that have no simple solution. In all, some 20-30 oncology nurses, who received oncological and/or palliative training in Israel or abroad, work in the community. All of them are available by telephone 24 hours a day, though most of them will not make house calls after working hours, because they are not reimbursed for these. In addition, they play a central role in coordinating hospital and community services, developing and implementing oncology and palliative projects in their district, training medical personnel, and overseeing this type of care in their district.
- ◆ ***Home hospice:*** There are seven home hospice units in Israel. They are dedicated to serving people who are dying in the community and their families. Four of the units are implemented by Clalit Health Services, two are implemented by the hospice departments of large acute hospitals, and one is implemented by an independent association. All of them are funded in several ways, including direct budgets from Clalit Health Services, the sale of services to other health plans, and donations – from philanthropies such as the Israel Cancer Association and American Jewish Federations, and from private benefactors. Consequently, there is no steady supply of funds to these units, making their existence precarious, and impeding their ability to expand their activities.

3. Patterns of Formal Care in the Home Hospice Units

- ◆ ***The frequency of physician and nurse visits:*** Thirteen percent of the patients were visited by a physician more than once a week, 45% were visited once a week, and 13% were visited between two and three times a month. Twenty-nine percent of those registered with a home hospice unit were visited by a physician less than once a month, once only, or not at all. A nurse visited the homes of patients with greater frequency: 44% of the patients were visited by a nurse more than once a week, 37% were visited once a week, 9% were visited several times a month, and 10% were visited once a month or less. A summary measure of physician and/or nurse visits revealed that at least one (or both) of these professionals visited 45% of the patients more than once a week, 39% of the patients once a week, and 16% of the patients less than once a week. A multivariate regression analysis revealed that more than one visit per week by a physician and/or nurse were independently correlated with suffering from symptoms to a very

great extent, death within a month of the interview (that is, within a short time), and lack of involvement in care of the community clinic concurrent with the home hospice.

- ◆ ***The accessibility of home hospice staff:*** Although a physician and/or nurse from the home hospice was available in person and by telephone 24 hours a day, only 80% of the patients contacted them in an emergency. Twenty percent of the patients sought help in an emergency from their community clinic, an emergency medical center, a hospital, or an emergency room. Eight percent (19) of the family caregivers reported encountering a problem "after hours" to which they did not receive a satisfactory solution; half of them cited physicians in this regard.
- ◆ ***Visits by a social worker and other medical personnel:*** A social worker visited 39% of the patients on a regular basis, 34% of them once, and 27% not at all. She maintained telephone contact with 39% of the patients – usually those whom she had also visited. A minority of the patients (1%-14% in different units) were treated by a physiotherapist, occupational therapist, psychologist, nutritionist, or alternative therapist; 7% were visited by a volunteer.
- ◆ ***Additional health services:*** Nearly two-thirds (64%) of the patients registered with a home hospice unit were treated concurrently by another service, usually a community clinic (61%) or hospital oncology services (42%). Only 36% of the patients were treated by the staff of the home hospice unit only, 25% were treated by two service providers, and 39% were treated by three service providers. More of those whose functioning was normal were treated by additional health services but as a patient neared death, clinics and hospitals tended to cease treatment. Most (82%) of the caregivers reported that they did not receive contradictory instructions from different service providers; however, 12% reported that this did happen occasionally.

3. Quality of care in Home Hospice Units

- ◆ ***The patients' demographic, functional characteristics and severity of the disease:*** The average age of the patients was 69.3, 58% of them were women, 78% of them were insured by Clalit Health Services, and all of them suffered from metastasized cancer. The functional ability of 57% of them was at nursing care level, 30% had partial functional ability, and only 13% were independent. Close to one-fifth (17%) of them were semi-conscious. According to a summary measure based on the Edmonton Scale, 40% suffered to a moderate extent (that is, had 0-3 symptoms from which they suffered to a very great extent), 32% suffered to a great extent (4-6 symptoms), and 28% suffered to a very great extent (7-12 symptoms). The symptoms the patients suffered from most were pain, extreme weakness, fatigue, and lack of mobility. They suffered to a lesser extent from constipation, insomnia, lack of appetite, shortness of breath, nausea and vomiting, oral problems, dizziness, and diarrhea.
- ◆ ***The duration of treatment in the unit and place of death:*** The duration of treatment, from admission until death, of **all** of the patients admitted to a home hospice unit during the study (478 patients, including those who were not interviewed), was 130 days. The median was 66 days. About 14% were treated by a unit for up to two weeks before they died (the majority of these patients were not interviewed), 14% were treated for between two weeks and one month, 24% were treated for between one and three months, 14% were treated for between three and six months, and 23% were treated for more than six months. The time that elapsed between the interview (of 261 patients) and death was 95 days, on average; the median was 54 days. About 44% of all patients admitted to a home hospice unit (including those not interviewed) died at home. About 16% of them died in the hospital within 48 hours of admission (however, as some

of the units did not report the time elapsed between admission to the hospital and death, this assessment is incomplete); 27% died in the hospital or an institution; and 13% died in a hospital-based hospice more than two days after admission.

- ◆ ***The quality of physical care and emotional support:*** Most (88%) of the caregivers reported that, during the week preceding the interview, the patient had received exactly the correct dosage of medication to relieve pain. While 81% of the caregivers reported that the medical staff had explained how to cope with the patient's pain in a way they could understand, 19% reported on this in the negative. Only 62% of the caregivers reported feeling that the staff had sufficiently addressed the patient's fears and anxieties, and 38% reported feeling that the staff addressed this less than they should have. In addition, on questions summarizing the quality of care provided by home hospice staff during the past week, higher scores were given for physical care and communication than for emotional support to the family (8.2, 8.5, and 5.9, respectively, on a scale of 0-10).
- ◆ ***Receipt of information and involvement in decision-making and care planning:*** Most (83%) of the caregivers reported receiving information about the medications the patient was receiving to control his symptoms (e.g., pain, shortness of breath). However, 23% reported wanting more information than they were receiving. Most (82%) of them also reported receiving the right amount of information about the patient's medical condition. However, others reported feeling they were being given insufficient information. About half (47%) of the caregivers reported that someone on the unit staff had talked to them or the patient about the patient's medical care, and about 50% reported that someone on the unit staff had tried to ensure that treatment was meeting their wishes. However, about half of the caregivers reported the opposite.
- ◆ ***Satisfaction with the frequency of visits by unit staff:*** The majority of caregivers reported feeling that the physician and nurse visited the patient often enough. However, more than one-third of the caregivers of patients who were visited infrequently felt that the physician and/or nurse did not come often enough. Only 58% of the caregivers reported feeling that the social worker visited the patient often enough.
- ◆ ***The patient's quality of life:*** According to the McGill Quality of Life Questionnaire for Terminal Patients, which has been validated in Hebrew, the average score for overall quality of life was 3.6 (a scale of 0-10). The average score for suffering from discrete physical symptoms was 4.7, for suffering from psychological symptoms was 3.8 (the lowest score for a single item), for existential well-being was 5.2, and for support was 7.2. These findings are very similar to those found using the same tool in other countries.
- ◆ ***Burden on the primary caregiver:*** The average score for overall burden was 32.8 (a scale of 0-88 which representing the most severe burden). 24% of the caregivers reported that caring for the patient constituted a light burden, 42% reported that it constituted a moderate burden, and 34% reported that it placed a heavy burden on them. In addition, 34% of the caregivers reported that the financial burden arising from caring for the patient at home was extremely heavy, 33% reported that it was somewhat heavy, and 33% reported that they hardly felt it a burden at all. Caring for the patient had had a noticeable effect on their work: 68% had missed work hours and/or days during the past month (as had 53% of other family members), and 39% of them reported having left work to care for the patient.

4. Policy Implications

Dedicated palliative services and home hospice units exist in Israel to a limited extent. Even where these do exist, they cannot treat all of the terminally ill patients living in the community. Consequently, most individuals who wish to live out their final days in the community are cared for by community clinics, home medical care units, and hospital oncology departments, which not only do not incorporate the principles of hospice, but often are not even aware of them. Thus there appears to be a need to include dedicated palliative services in the uniform benefits package mandated by the National Health Insurance Law, so as to ensure that the health plans make them available to the extent and breadth that will enable anyone who is dying to receive them. It is necessary to establish eligibility criteria for palliative care and decide which services will be permitted to refer a patient for palliative or hospice care.

Although all home hospice units set procedures and determine the frequency of staff visits, physicians and social workers visited patients less often than was stipulated in the regulations of some of the units. It is therefore necessary to uphold regulations, and ensure that physicians visit the patients according to them. It is also necessary to examine existing regulations regarding the frequency of staff visits to patients, and adjust these to meet needs that are currently not being sufficiently met. It may be prudent to set flexible regulations, which will take into greater account the fluctuating treatment needs of the patient. This may require increasing the number of medical and social welfare staff in a unit, or expanding their positions.

Usually, physicians affiliated with a home hospice unit – not to mention with other community services that treat terminally ill patients – have no formal palliative training and have never worked in a palliative setting. This raises a need to develop frameworks that will train current and prospective staff in palliative care. It is important to provide palliative training to the staffs of community clinics, long-term care institutions, and old age homes – settings that may be expected to continue caring for the many terminally ill patients who may not be able to benefit from dedicated hospice services.

Since two-thirds of the patients were treated concurrently by a home hospice unit and other services, and since this pattern of care is to become more widespread in the future, the health care system must prepare for it. Services should ensure coordination between palliative and other services – especially given that nearly one-tenth of the informal caregivers interviewed reported receiving contradictory instructions from different treatment agents. It might be judicious to assign the task of coordination to oncology nurses, who now perform it *de facto*. To this end, it will be necessary to define their role as "case managers", anchor it in regulations, and inform all those involved in the treatment of patients.

The patients and their families are satisfied with the services received from home hospice units, especially the physical care. At the same time, a significant proportion of the caregivers reported wanting more information about the patient's illness and how to treat it. In addition, the need expressed for greater emotional and psychological support was notable. Given that psychological services are available to a limited extent in the health system as a whole, and to an even lesser extent as a component of palliative services, in particular, there is a need to improve care of the

patients' emotional, psychological and spiritual needs. It is also important to expand the network of volunteers, which at present is extremely limited in most of the units.

Although the home hospice units share a commitment to hospice principles, they were found to differ in their number of staff, work patterns, frequency of visits, and response to the patients' needs. It may thus be desirable to establish a basic, uniform set of services to be provided by all home hospice units according to defined principles and work patterns that will cover staff composition, visit frequency, types of treatment, and cooperation with other community and hospital services.

In summary, this study presents a comprehensive, up-to-date picture of community and hospital-based palliative and hospice services in Israel, and their strong and weak points. Given that many people will need these services in the future, and that every individual has a right to receive palliative care at the end of his life, there is a need to expand and develop them, increase their number, and determine the basic services they will provide. At the same time, thought should be given to offering alternative and partial "packages" of palliative services, which will consider the health system's limited resources while enabling the terminally ill to end their lives with dignity. At present, the support and hospice services offered in hospitals and the community benefit patients with cancer; only a minority of the patients who die from severe chronic diseases, which may be similar to terminal diseases, benefit from them. There is a need to enable these patients, too, many of whom are elderly, to receive hospice or palliative care in the community, in old age homes, and in long-term care institutions, as this may reduce their suffering, thereby improving their quality of life at the end of life.