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Use of Healthcare Services, Quality and Cost of Care of Terminal Cancer Patients

Netta Bentur ◆ Shirli Resnizky Sophia Eilat-Tsanani ◆ Ran Balicer

The study was conducted with the support of a grant from Guy and Nora Barron, Michigan



RESEARCH REPORT

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Bentur, N.; Chekhmir, S. Szlaifer, M.; Singer, Y.; Schwartzman, P. 2007. *Nationwide Palliative Training Program in Israel: Evaluations Study*. RR-498-07.

Bentur, N.; Resnizky, S.; Shnoor, Y. 2005. *Palliative and Hospice Services in Israel*. RR-459-05.

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Executive Summary

1. Introduction and Study Goals

In recent decades, end of life care has become of central concern to health systems. The aging of the population, changes in morbidity that have caused a shift 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.

Since many of those suffering with cancer are older adults, and since their physical functions, health and social status are highly variable, the challenge to assess them properly and optimize their individual treatment is growing. There is a widespread appreciation that geriatric-specific orientation and tools can help better define standard care for older individuals with cancer.

Health systems in the west have come to realize that palliative services – services that improve the quality of life of patients and their families facing problems associated with life-threatening illness - are the most appropriate for patients at the end of life. Palliative care relieves suffering by means of early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems.

However, according to epidemiological research and assessments, only about 10%-15% of Israeli cancer patients receive palliative care. The approaches and care concerning patients of metastasized cancer are far from satisfactory. Patients and families feel helpless and frustrated in view of the limited services available, the absence of information and the lack of awareness about the provision of suitable care during this last period of life. Therefore, this study aims: to broaden the understanding of how to improve services for cancer patients; to assess the quality of care provided by different frameworks; and to compare the costs of care provided by them. The study follows previous studies on hospice and palliative care carried out by the Institute, with the support of the Jewish federations of Detroit and New York. These studies played a major role in the development of the model of hospice in Israel and in the decision by the Ministry of Health to issue directives (issued by the Ministry's director general in 2009 defining standards for the development and provision of palliative care in health settings.)

In this study, we are specifically interested in the quality and cost of care for patients who received home-hospice in comparison to other frameworks of care, such as community clinics, general hospitals, oncology day-hospitals, and nursing homes.

The study aims to assist the Ministry of Health in the ongoing implementation of the directives and promote the ongoing development of effective hospice care.

2. Study Design

The study design had two components:

- a) An analysis of the administrative data on all patients who had died of metastasized cancer in the northern district of the Clalit health plan during a nine-month period from December 2008 to August 2009. Data that was collected included services used by patients and the costs incurred.
- **b**) Personal interviews with family members of the deceased provided information on quality of treatment.

The study target population comprised 559 deceased people who had died in the given nine months from a malignant illness, according to the Clalit health plan register. Of these, 429 (75%) matched the study requirements. The other 25% had suffered from a malignant illness at some point in their lives, as noted in the list of their diagnoses, but this illness had not been the cause of death. Personal interviews were conducted with family members of 193 deceased (45%). In the case of more than half of the deceased (55%), there were no interviews with family members for various reasons: some refused, some were away, and some could not be contacted.

3. Summary of Findings

Characteristics of the Population

Slightly more than half the patients who died of metastasized cancer (56%) were men. Their average age was 69, 33% were 64 or less, 41% were 65-79, and 26% were 80 and over. Close to half (44%) were native Israelis, and 30% had immigrated since 1990, mostly from the former Soviet Union (FSU). Similar to the district population, 73% were Jews and 27% Arabs. Twentynine percent were from the Galilee Administrative region; 39% from the Amakim Administrative region and 32% from the Nazareth Administrative region.

Use of Healthcare Services and Cost of Care

The vast majority of patients (95%) had visited (or been visited by) a family physician once a week on average, and most (87%) had been hospitalized for 19 days on average during their last six months. Forty-eight percent had visited the emergency room an average of two times, and 42% had been treated with chemotherapy or radiotherapy in day-hospital, receiving an average of 7.5 treatments. Fifty-nine percent had been treated with opiate medication in the last six months of life. More than half of service usage occurred during the patients' last six months - particularly the rate of hospitalization and emergency room visits (68% were hospitalized in their final month and 20% visited to the emergency room). Yet only 48% received opiate medication for pain relief in the last month of life.

The *average cost* of care per patient¹ in the last six months of life was NIS 63,586. The large standard deviation (NIS 67,596) and the median (NIS 46,717) reveal that a small number of "very expensive" patients raised the average cost per patient. The average cost of care per patient in the final two months was NIS 37,715, i.e., 59% of the total average cost in the last six months; here too, the standard deviation (NIS 30,330) and the median (NIS 22,913) reveal that a few patients were particularly expensive.

Two-thirds (68%) of the expenses in the last six months of life were incurred for general hospitalization while the remainder went toward medications, home-hospice, oncology day-hospital and nursing homes (in the northern district, nursing homes serve as an alternative to inpatient hospice care). These costs do not include services and treatment received at the health-plan clinic - such as visits to a physician or a nurse, or the receipt of medication. In the last two months of life, the proportion of costs for general hospitalization rose from 68% to 76% while the proportion of the other components decreased somewhat.

Perceived Quality of Care

We asked the family members of the 193 deceased to cite the dominant care provider (DCP) during the acute, severe stage of the illness as defined by family members (a period of 77 days on average). They pointed to five DCPs: 36% cited the community clinic; 20% – the day-hospital unit; 18% – the hospital; 16% – the nursing home; and only 10% – the home-hospice unit.

Twenty-five per cent of the 193 deceased (49 patients) whose relatives were interviewed had received home-hospice care, yet home-hospice care was the DCP for only 10% (20 patients). For the remaining 15% (29 patients), other care providers were dominant.

The *quality of care* of patients who had died of cancer was examined by means of four parameters commonly used in the literature: contact with the physician; the professionalism of the nurses and physicians; communication with and involvement of the patient in decision making; and the personal wellbeing of the main family caregiver. For the first three parameters, the quality of care was found to differ by DCP: home-hospice as the DCP received the highest average score, followed by the day-hospital unit. The scores for the community clinics, the general hospitals and nursing homes were lower. Overall, the average score for the personal wellbeing of the caregiver parameter was lower than for the other three, which relate to direct patient care, and no differences were found between the five DCPs.

When controlling for age, gender and population group (Jews/non-Jews), there was a significant relationship to higher scores for the three first parameters (i.e. all parameters except personal wellbeing) when the place of death was at home compared to at the hospital or at a nursing home. When DCP was home-hospice care there was a significant relationship with higher scores for contact with the physician and the professionalism of the nurses and physician. When DCP was

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¹ The cost shown is a similar price, but is **not** identical to the real price. For this purpose we used the base price as 100 and then standardize the rest of the costs according to the ratio between lowest cost and the base.

oncology day-hospitals there was a relationship with higher scores for the professionalism of the nurses and physicians and communication on decision making.

Characteristics of Home-Hospice Care vs. Care Provided by Other Health Services

We found that a similar proportion of patients who received home-hospice care — whether or not they had chosen it as the dominant care provider — received opiate medication in the severe, final stage of illness (95% and 90% respectively), whereas only 68% of patients without home-hospice care received such medication. Additionally, when home-hospice was the chosen DCP (hereafter, home-hospice/DCP) caregivers believed that the patient's receipt of pain-management medication had been appropriate (87%) compared to when patients were treated by home-hospice not as the chosen DCP (73%, hereafter, home-hospice/non-DCP) or not treated by home-hospice at all (72%, hereafter, no home-hospice). The advantage of home-hospice/DCP was especially prominent in the treatment of emotional symptoms. Thus, 88% of family members of patients with home-hospice/DCP reported that the patient had been treated for anxiety, and 78% reported that the patient had been treated for depression as compared with only about a third of the family members who reported treatment for anxiety in the other two groups. Lastly, palliative sedation as part of the treatment was much higher among those with home-hospice/DCP than in the other two groups (45% and 25% respectively).

Far more patients with home-hospice/DCP were treated according to the principles of palliative care (receiving explanations on patient rights, including the patient and the family members in decision making, continuity of care, writing advance directives, dying at one's place of choice, foregoing curative medication at the end of life etc.) than did patients with home-hospice/non-DCP or patients with no home-hospice.

The average cost of care in the last six months of patients with home-hospice/DCP was 15% lower than the average cost for patients with home-hospice/non-DCP, and 26% lower than for patients with no home-hospice. The gap between the groups widened in the last two months of life: the average cost of care of patients with home-hospice/DCP was 30% lower than for patients with home-hospice/non-DCP, and 42% lower than for patients with no home-hospice. Hospitalization accounted for 24% of the costs of patients with home-hospice/DCP, 37% of the costs of patients with home-hospice/non-DCP, and 64% of the total expenditure for patients with no home-hospice.

4. Conclusions and Programmatic Directions

The study yielded significant information concerning the care of patients with cancer in Israel. It provides a basis for improving the services and the quality of life of the dying patients and their families. The following are among the major discoveries:

• About two-thirds of the patients in this study who died of metastasized cancer were age 65+ and about a quarter were 80+, similar to rates in other Western countries. For many reasons, older adults with cancer have different needs than younger adults with the disease. Treatment for older adults needs to consider many issues and therefore the field of geriatric-oncology has been developing rapidly during the last decade. While information on the needs of elderly

patients suffering from and dying of cancer has grown globally, in Israel more attention for the special needs of this group is required, and a palliative approach needs to be developed. We should expand our knowledge, awareness and understanding of palliative care for severely ill older adults while addressing their characteristics – a field that is far from satisfactory in Israel.

- Half of the patients received opiate medication for pain relief though the vast majority of patients with metastasized cancer suffer from pain and, in their case, opiate medication is considered best practice. Thus, there is an urgent need to examine the knowledge and approaches of family and hospital physicians concerning the indications for these medications. If necessary, educational activity and instruction should be offered on the subject.
- Although the patients were treated concomitantly by many providers at the end of life, family members were nonetheless able to point to the dominant care provider: only about 10% of the family members cited home-hospice as the DCP in the final stages of the patient's life, although there are two home-hospice units in the northern district. An additional 15% of the patients also received home-hospice care, but it was not cited as their DCP. The low utilization rate of home-hospice/DCP appears to be one of the most important challenges to emerge from the study. The challenge requires further understanding in order to expand the utilization rate of home-hospice services. For this purpose, discussions might be held with the district directors of the health plan, the directors of the home-hospice units and of other district services to examine the patterns of referral to home-hospice and to discuss with them the possibilities for expanding referrals. Discussion should also be held with other key parties and decision makers in the district who might be able to help increase both the referrals to home-hospice and its involvement in the care of terminal patients.
- ◆ The advantage of home-hospice as the dominant care provider was striking. Patients treated by home-hospice received more doses of opiate medication, and many more of them were treated for emotional symptoms such as anxiety and depression. In addition, most died, according to their wishes, at home, as compared to less than a third of the patients with home-hospice/non-DCP or with no home-hospice about 70% of whom had wished to die at home. This finding emphasizes the need to make every effort to supply services that respect a patient's wishes to die at home. At the same time, thought should be given to the burden carried by family members and to responding to their needs to the extent possible.
- In all settings, the average score for the three parameters of quality of care, which relate to direct patient care (contact with physician, professionalism of the nurses and physicians and communication), was higher than the average score for the caregiver's personal wellbeing, despite the importance attributed to the difficulties of the main caregivers of the severely ill. This issue requires further consideration. Ways should be found to provide more support through social services, support groups and other means to family members caring for the severely ill at the end of life.

- As opposed to other services, the home-hospice and the oncology day-hospital in Nazareth showed a distinct preference for caring according to palliative principle. It is therefore important to provide palliative care education and training to the medical staff of community clinics and hospitals that bear the burden of care for most of these patients.
- The patients used many services near the end of their life, especially in the last two months. The average cost of care per patient exceeded sixty thousand NIS in the last six months of life; about 60% of this sum was incurred in the last two months of life, and about half was spent on hospitalization. The cost of care for a few patients was much higher than the average cost, amounting to hundreds of thousands of shekels in a six-month period. Consequently, there is a need to deepen the investigation of the services and treatments received by the particularly "expensive" terminal patients. The efficiency of their care, whether there were alternatives, and, if so, whether they were considered or offered to patients needs to be examined.
- ◆ The cost of care in the last six months of patients treated by home-hospice/DCP was lower than the cost of care of patients treated by home-hospice/non-DCP or no home-hospice. This difference due largely to the cost of general hospitalization was particularly evident in the last two months of life, amounting to as much as 40% of their cost of care in comparison with costs for patients not treated by home-hospice.
- In light of the study findings on the advantage of home-hospice in terms of both quality of care and cost, greater utilization of this service may lower the costs of care perhaps for the most expensive patients in particular without detracting from indeed, even while improving the quality of care.
- The present study was limited in that about half of the family members of the deceased were not interviewed and they differ somewhat in characteristics from the family members who were interviewed. This limitation stems from restrictions imposed by the ethics committees (Helsinki committees), and from the study design, which made it necessary to contact family members through the family physician. Thus, only community treated patients could be approached. The examination of quality of care may therefore have focused on patients who received more treatment than others did.

In summary, the study findings reveal that despite the quality of care of patients treated by home-hospice services - which are based on the principles of the palliative approach - being higher and the cost of care being lower than those of patients who received the other methods of end of life care, few patients received these services. Every effort should be made to increase the number of patients treated by palliative services at the end of life to improve both the efficiency and the quality of care of these patients.

The findings were presented to decision-makers in Israel's Ministry of Health, to health plans and to service providers as well as to the UJA Federation of New York and other involved organizations. The study provides insight into decision-making and policymaking regarding the development of palliative services and hospice units in hospitals and the community. It serves as

an informed basis for the continuing implementation of the directives of the director-general of the Ministry of Health requiring all healthcare settings to implement palliative care for patients suffering from incurable diseases within three years. The research team continues to be involved in the development and evaluation of these processes.

The study was conducted with the support of a grant from Guy and Nora Barron, Michigan.

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1. Introduction and Study Goals

In recent decades, end of life care has become of central concern to health systems. The aging of the population, changes in morbidity that have caused a shift 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. Since many of those suffering with cancer are older adults, and since their physical functions, health and social status are highly variable, the challenge to assess them properly and optimize their individual treatment is growing. There is a widespread appreciation that geriatric-specific orientation and tools can help define standard care for older individuals with cancer (Lichtman et al. 2007, Exterman and Hurria, 2007, Repetto et al. 2002).

Health systems in the west have come to realize that palliative services – services that improve the quality of life of patients and their families facing problems associated with life-threatening illness - are the most appropriate for patients at the end of life (). Palliative care relieves suffering by means of early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems.

Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy; and includes those investigations needed to better understand and manage distressing clinical complications. (http://www.who.int/cancer/palliative/definition/en/.)

The first country to begin discussing shifting responsibility for the dying process away from the medical profession was the UK. In 1967, Dame Cicely Saunders founded the first ever modern hospice, the St. Christopher Hospice in London (Saunders, 1984). Many western countries embraced the idea of hospice care. In 1969, Florence Wald, invited Saunders to the US to learn from her experience (Saunders and Sykes 1993, Clark et al. 1998). The overwhelming satisfaction of patients and families served by her freestanding hospice proved that the concept was not only feasible but also desired. It incorporated an array of services - ranging from inpatient care, home care, clinic care, to bereavement counseling for families - into an existing medical center. During the seventies, several hospices were opened in the US, in Connecticut, Chicago and in New York (Saunders and Sykes, 1993).

In the 1990s the United States Supreme Court declared hospice and palliative care as a human right for all, leaving to the individual states the creation of laws concerning assisted suicide and euthanasia. Public perception had already established hospice care as the culturally expected

standard of care for the terminally ill. Much of the successful dissemination and development of service capacity in the US was due to the funding of the Center to Advance Palliative Care, and the finding by researchers of empirical data - against the backdrop of rising health care costs - pointing to the advantages of hospice care and to the need to move it forward rapidly (Morrison et al. 2005, Morrison et al. 2009, Carlson et al.2009). Longstanding policy and acceptance of palliative care principles have allowed services to proliferate in the United States.

In Israel, public support, policy and the scaling up of service provision has taken a slower course. The belief that every individual has the right to palliative care at the end of life is gaining ground, but has yet to be widely accepted (Clark, 1998, Bingley et al. 2008). The sanctity of life (*kedushat hakhayim*) is a central value in Israeli society (Glick, 1997, Barilan, 2003, Kinzbrunner, 2004), which contributes to the view that all medical means must be used to save life - including expensive, heroic means that may only have a small chance of success. However, large segments of the public and health professionals are opposed to this outlook (Clarfield et al. 2003). Health care providers in Israel face the challenge of respecting personal autonomy and supplying quality end-of-life care, while also taking traditional values into account (Zemishlany and Nahshoni, 2009). However, many of the providers are not aware of palliative care precepts and have not been trained in those skills (Bentur, 2008). Many Israelis fear that, in the terminal stages of their lives, they will receive more medical care and less pain relief than they wish (Carmel, 1999).

The uniform benefits package mandated by the National Health Insurance Law, which dictates the services and medications the health plans are obligated to provide to their members, does not currently include a detailed definition of services for the dying; nor have eligibility criteria for such services been determined. While the health plans do provide various services to patients who are dying, to date there is no comprehensive information on these services and activities. In addition, one of the key catalysts for changing the norms of palliative care practice is more professionals and education (Emanual, 2008). Yet, there are only a few physicians in Israel with formal training in palliative care. There are, meanwhile, many more nurses than doctors who have studied palliative care in Israel or abroad. Although palliative education is gradually expanding, the needs are much greater than what is available today (Shvartzman et al. 2011, Livneh, 2011).

Responding to prolonged public pressure, the government has initiated efforts to tackle end-of-life issues. In 2000, Israel's Minister of Health established a public committee on the sensitive issue of end-of-life care. The committee was chaired by Rabbi Avraham Steinberg – who is also a professor of medicine – and included representatives of different Jewish denominations, the larger minority groups within Israel, physicians, philosophers and ethicists (Steinberg and Sprung, 2005). In 2005, the Dying Patient Act was enacted in Israel (State of Israel, 2005). Interest in developing palliative services in Israel began about three decades ago (Waller et al. 1987, Waller, 1997). During the late 1980s and the 1990s, eight home-hospice units were opened across the country, supplying palliative care for cancer patients. However, they dealt almost exclusively with cancer patients and did not provide for patients with chronic illnesses. They rely

on multiple sources of funding, such as Clalit's Health Plan budgets, the sale of services to other health plans, and, primarily, philanthropic contributions. Consequently, there is no steady supply of funds to these units, making their existence precarious, and impeding their ability to expand their activities (Bentur et al. 2005, Zemishlany et al. 2009).

In 1994, the Shaare Zedek Medical Center established the first cancer center fully integrating oncology and palliative care services (Cherney, 1996, Cherney, 2009). This initiative was followed by the development of similar services, but today, only three of the country's 15 cancer centers have developed fully integrated oncology and palliative medicine programs which include a high level of integration of services within the hospital and incorporate the use of homecare services.

The Myers-JDC-Brookdale Institute has monitored the issue of palliative care from the start. As early as 1995, a study was carried out surveying Israel's hospice services (Primak & Brodsky, 1995). The study was initiated and funded by ESHEL and the Jewish Federation of Detroit, that has been interested in developing hospice services in Israel for many years. Ten years later, also with the support of ESHEL, and with additional funding from the National Institute for Health Policy Research, the Institute carried out a comprehensive, updated review of palliative and hospice services in Israel providing up-to-date data on their characteristics, cost and quality (Bentur, Resnizky, Shnoor, 2005). The findings of this study were widely distributed and informed the work of a committee appointed by the director general of the Ministry of Health, whose recommendations for setting guidelines for palliative care were adopted in full by the ministry. Further, presentations of the findings to the Israeli and US offices of the UJA Federation of New York alerted them to the importance of developing palliative and end-of-life services in Israel and supported their decision to contribute to the improvement of these services. In 2005 the Federation spearheaded the development of a national training program in palliative care. An MJB study, supported by the New York Federation and ESHEL, examined the program during 2006 (Bentur, & Chekhmir, 2007). To complement the focus on training, the New York Federation also launched a major funding initiative for development and provision of spiritual care services, aimed at supporting people with serious illnesses and providing them with the space and time to address the existential and spiritual aspects of their life. The Institute carried out an in-depth, systematic overview of the program over three years. The report on this study (Bentur & Resnitzky, 2009) served as a basis for the continued development of spiritual care programs in Israel. Following the 2007 and 2009 reports, in mid 2009 the director-general of the Ministry of Health issued a directive policy statement defining standards for the development and provision of palliative care services for hospitals and health plans and requiring all healthcare settings to implement palliative care for patients suffering from incurable diseases within three years (State of Israel, 2009).

Despite these developments, currently only about 10%-15% of cancer patients receive palliative care and hospice services designed to reduce their suffering of pain and other symptoms, and improve their quality of life during their final days (Bentur et al 2005, Bingley at al. 2009, Bentur & Resnizky 2009). Family members of terminal patients feel helpless and frustrated in view of

the few services and little information available, and the lack of awareness about suitable care for end-of life patients.

Therefore, the goal of this study was to broaden the understanding of how to improve both services and the quality of care for terminal patients. Specifically, it sought to examine the patterns of care of patients dying of metastasized cancer, the quality of care provided by different frameworks and their costs, in order to gain understandings that will improve the provision of services and enhance the quality of patients' end of life. The findings of this report will inform and provide input to the ongoing implementation of the 2009 directives.

2. Study Design

The study design had two components:

- (1) To examine the patterns and scope of care of patients with metastasized cancer and the costs involved in the last period of life, we analyzed files of administrative data on all deceased enrollees of the Clalit health plan who had died of metastasized cancer in the northern district during the nine-month period of December 2008 to August 2009.
- (2) To examine the quality of care of different frameworks, we interviewed family members of the deceased.

2.1 Study Population

The study population was selected in three stages: every two months, the names of those who had died with malignancy as one of the diagnoses on their diagnosis list were drawn from the Clalit health care file in the northern district. In the second stage, to verify the cause of death, i.e., that the patient not only had but, in fact, died of metastasized cancer, brief telephone interviews were conducted with the patient's family physician. After the physician verified the cause of death as metastasized cancer, s/he was asked to turn to a family member who had been the main informal caregiver and obtain her/his consent to an interview. Lastly, the family member was asked if the patient had suffered from a malignant illness, which had been the cause of death.

In the given nine-month period, 559 people who had been diagnosed with a malignant illness died according to the Clalit file on the deceased (out of 745 people over the year). Of these, 429 (75%) matched the requirements of the study, i.e., died from their malignancy. The other 25% had suffered from a malignant illness at some point in their lives, as stated in their list of diagnoses, but the malignant illness had not been the direct cause of death. This fact, as stated above, was confirmed in the interview with the family physician and with a family member.

In the next stage, we conducted face-to-face interviews with 193 family members (45%) of the deceased; family members of 55% of the deceased were not interviewed. More than a third (39%) refused to be interviewed, mainly because of the emotional difficulty involved. About a third (32%) were not interviewed because the family physician had failed to contact the family member, despite repeated reminders on our part. In these cases the physicians reported that they did not know the patient or the family since the patient had been in a nursing home or had died

shortly after the illness was discovered and that, therefore, they had not treated the patient during the acute stage of the illness. For 38 of the deceased (16%), particularly those in a nursing home, we could not find family members able to report on the care of the patient and 13% were not interviewed for other reasons; e.g., they did not live in the northern district and therefore were not familiar with the details of care provided their relatives (see Figure 1).

A high proportion of the interviewees, as opposed to the non-interviewees, lived in towns rather than rural (Jewish or Arab) villages, and many of them were immigrants from the former Soviet Union (FSU) who had arrived in Israel since 1990. Additionally, a high proportion of the interviewees' deceased relatives received services in the community (i.e., seeing a physician in the clinic or at home, home-hospice care or treatment at the unit for further care). In other words, since the contact with the family member was made through the family physician, and more patients who received care in the community were known to the family physician, we were therefore able to reach many family members whose loved one's had received treatment at home or in the community – and not in a hospital.

559 deceased diagnosed with cancer in Clalit Healthcare Northern District, December 2008-August 2009 **Included in study: 75% Omitted from study: 25%** 429 127 did not die of a were not treated died of a malignant in the district illness malignant illness 193 (45%) 236 (55%) family members family members not interviewed* interviewed * * Main reasons: 38 (16%) 429 No family member Refused 91 (39%) administrative data Difficulty contacting the obtained the doctor 76 (32%) Other reasons 31 (13%)

Figure 1: Study Population

2.2 Methods and Research Tools

In keeping with the study design, the research methods comprised two components. The first was data mining of the administrative data file obtained from Clalit health care, which included information on the patterns of use of healthcare services and their cost in the last half year of life. The second was a face-to-face personal interview with a family member of the deceased, conducted – on average -seven months after the patient's death. The interview relied on a structured, closed questionnaire, constructed for purposes of the study. The interview was conducted by trained interviewers who received oral and written instructions from the study team and were closely supervised. Finding will indicate which source provided the data.

The study was approved by the Ethics Committee (Helsinki Committee) of Clalit health plan.

3. Findings

3.1 Population Characteristics

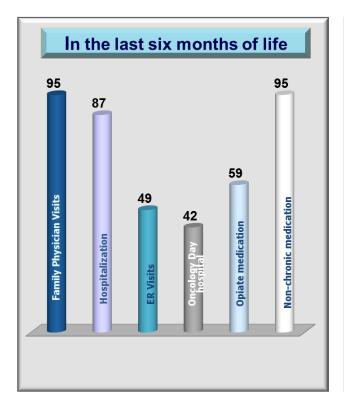
About 56% of the patients who died of metastasized cancer were men. Their average age was 69; 33% were 64 or less, 41% were aged 65-79, and 26% were 80 and over. About 44% were native Israelis, while 30% had immigrated to Israel since 1990, mostly from the former Soviet Union. Similar to the district population, 73% were Jews and 27% Arabs. Twenty-nine percent were from the Galilee Administrative region, 39% were from the Amakim Administrative region and 32% were from the Nazareth Administrative region (see Appendix I, TableI-1).

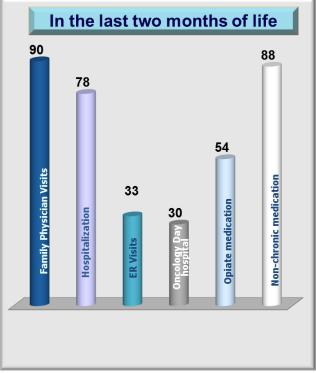
3.2 Patterns of Use of Healthcare Services

These patients suffering from metastasized cancer received a substantial amount of treatment in the last period of life and made extensive use of a variety of healthcare services. To learn about the patterns and extent of use of services, we analyzed the administrative records of the health plan for the last six months and for the last two months of a patient's life. Figure 2 shows that in the last half-year of life, 95% of the patients visited (or were visited by) their family physician and 87% were hospitalized. They saw the family physician once a week on average and were hospitalized for an average of 19 days (from 1 day to 169 days; standard deviation, 20.0; median, 14). Also, 49% visited the emergency room twice on average in the last half year of life. Forty-two percent were treated with chemotherapy or radiotherapy in an oncology day-hospital, receiving an average of 7.5 treatments; 59% received opiate medication for pain.

Almost all the patients concurrently received many additional medications to treat other symptoms of the illness, such as nausea or diarrhea, as well as medication – such as antibiotics - for other conditions.

Figure 2: Health Service Usage (%)



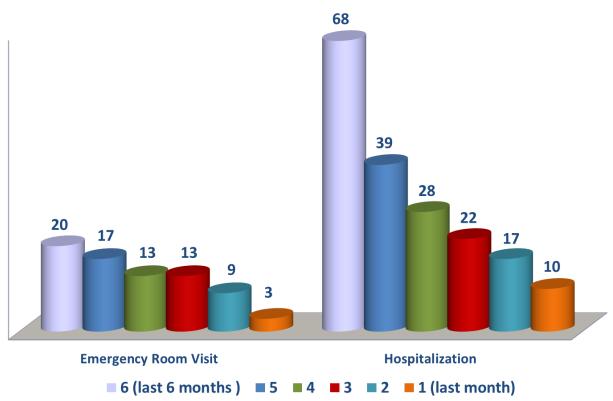


The study found that more than half of the use of services by patients during the last six months of life occurred in the last two months of life (including hospitalization days in a general hospital, emergency room admissions and oncology day-hospital usage). Nearly half of all the family physician visits and receipts of opiates and other medications during the last six months of life occurred in the last two of those six months.

The extent of the increase in the rate of emergency room visits and hospitalization **by month**, which occurred mainly close to the time of death, is illustrated in Figure 3.

About a fifth of the patients were treated with chemotherapy and radiotherapy in each of the last five months of life, a fact that deserves attention although we do not know whether these treatments were life-prolonging or palliative. We found that although towards the end of life the use of opiate medication increased, only less than two thirds of the patients received opiate medication in the last month of life and one third did not receive opiates in the period closest to death.

Figure 3: Use of In-Patient Services, by Month, in Last Six Months of Life (%)



As regards the characteristics of patients in terms of services consumed in the last half year of life, a multivariate analysis (see Table 1) and a bivariate analysis found that younger patients tended to visit emergency rooms, be hospitalized and use oncology day hospitals more than older patients. In addition, patients from the Nazareth Administrative region visited a general hospital and emergency room more frequently, to a significant extent, than patients from the Amakim Administrative region. Patients from the Nazareth Administrative region also utilized the oncology day-hospital unit to a significantly greater extent than patients from the Amakim Administrative region. This finding is not surprising since the oncology day-hospital unit is located in Nazareth.

In addition, fewer visits to the emergency room and to the oncology day-hospital showed a significant independent relationship with more visits to (or by) the family physician. This finding may indicate that patients who were treated by their family physicians to a greater extent, received better system-wide care.

Table 1: Usage of Services in the Last Half Year of Life of Deceased Cancer Patients, by Characteristics of the Patients and of the Service System (Logistic Regression); (N=429)

	General Hospitalization		Emei	gency Room	Oncolog	y Day Hospital
	В	Standardized Coefficients	В	Standardized Coefficients	В	Standardized Coefficients
Patient's age (continuous)	027	.973**	016	.984**	047	.954***
Population group: (Jews vs. Arabs)	459	.632	.265	1.304	.134	1.144
Administrative Council: Galilee (vs. Amakim) Nazareth (vs. Amakim)	.394 .713	1.483 2.041*	616 455	.540 .635**	.044 592	1.045 .553**
Visits with family physician (continuous)	.027	1.027	.034	1.035***	.024	1.024***
Visits with Nurses	.506	1.659	.192	1.212	.047	1.049
Received home-hospice	399	.671	.115	1.122	081	.922
Received other home-care services	.165	1.180	.283	1.327	.008	1.008

^{*}p<0.08 **p<0.05*** p<0.01

3.3. Cost of Care

The average cost of care per patient² in the last six months of life was NIS 63,586 and reached as high as NIS 691,896. The very large standard deviation (NIS 67,596) and median (NIS 46,717) reveal a right long-tailed distribution; i.e., a small number of "very expensive" patients greatly increased the average cost per patient. Moreover, the average cost of care per patient in the last two months of life was NIS 37,715, which accounts for 59% of the average total cost in the last six months. The average cost in the last two months of life reached NIS 222,542. Here, too, the large standard deviation (NIS 30,330) and median (NIS 22,913) reveal that a few patients were particularly expensive. Regarding the factors related to the cost of care – when controlling for other patient characteristics - a significant difference was found according to the patient's age: younger patients' had higher costs of care, and an increase in age was related to a decrease in the cost of care. No independent influences were found for the three administrative councils.

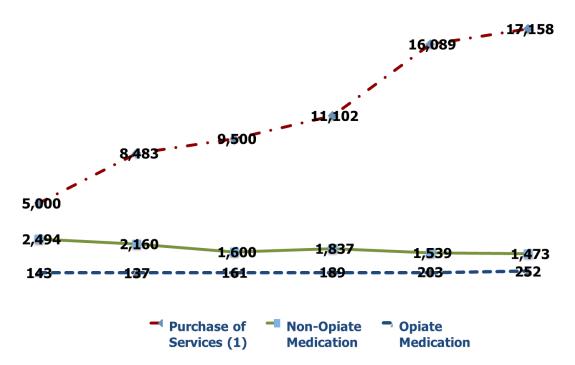
Figure 4 presents the average cost of purchases and medication for every month in the last half year of life. Most of the expenditure was on "purchases," a term that represents the expenditure of the health fund on the services received by a patient, such as hospitalization, visits to the emergency room, oncology-day care, outpatients clinics in hospitals, home-hospice, home-care units and nursing homes (in the absence of inpatient hospice) and excluding services and treatment at the health-plan clinic, such as visits to a physician or a nurse and receipt of medication from them. There was a dramatic increase in the average cost of "purchases" in the

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² The costs shown is a similar price, but not identical to the real prices. For this purpose we used the base price as 100 and then standardize the rest of the costs according to the ratio between lowest cost and the base.

last two months of life, compared with preceding months. The expenditures on opiates and other medications constituted a small share of the total expenditure, remaining stable through the last six months of life.

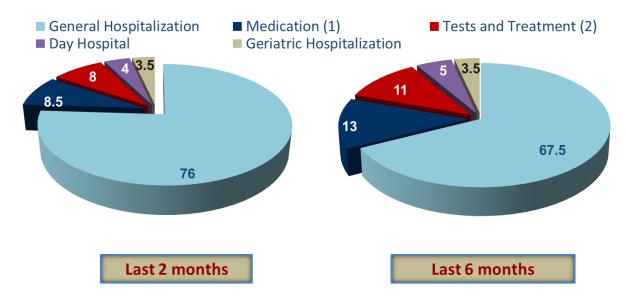
Figure 4: Average Cost per Patient, by Month, in Last Six Months of Life (NIS)



^{*}Standardized according to the prices of the Ministry of Health for Day Hospitalization, Including: Emergency Room, Hospitalization, Oncology Day Hospital, Home Hospice, Homecare and Nursing Homes

According to the findings, in the last half year of life, the expenditure on general hospitalization amounted to 67.5% of the total expenditure for a patient with the remainder going towards medication, oncology day-hospital treatments, and hospitalization in a nursing home (which, in the north, serves as an alternative to inpatient hospice care as the latter service is unavailable there). Examining expenditure in the last two months of life, we found that the general hospitalization component rose to 76% while the costs of the other components decreased somewhat (Figure 5).

Figure 5: Distribution of Expenditure (%) What is the money spent on?



- 1. Opiate medication, other pain killers and non chronic medication
- 2. Emergency (1%), radiation and chemotherapy (1.3% two months; 2.6% half year), imaging and laboratory tests (2% two months; 2.7% half year), home hospice (3% two months; 2.4% half year), Unit for Home Care, oxygen and other respiratory equipment

3.4 Perceived Quality of Care

One important component of the examination of quality of care was the subjective perception of the family members of the deceased. Quality of care was examined in this study by means of the CANHELP questionnaire, which is used by researchers in North America and is considered valid and reliable (Heyland al. 2010). The questionnaire consists of six parameters of quality, four of which were relevant and therefore used in the present study:

- 1) Contact with the physician;
- 2) Professionalism of the nurses and physicians;
- 3) Communication with family/patient and their involvement in decision making;
- 4) Personal wellbeing of the main family caregiver.

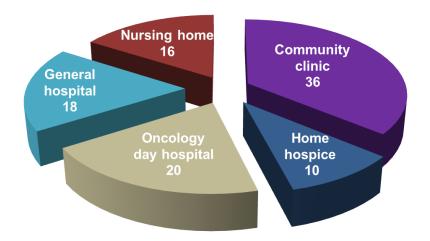
The first three parameters relate to patient care while the fourth – though not focusing directly on patient care – is highly important in the perception of the overall care received by terminal patients. The scores for each parameter ranged from 0-100.

To examine the quality of care of dying patients, we focused on the severe, acute stage of illness culminating in the patient's death. The duration of this period was estimated by the response of the family member to the following question: "The period during which the patient suffered from

the illness may be divided into two: the first period, from the discovery and diagnosis of the illness until the onset of the severe, terminal stage; and the second period, which is in fact the raging, severe stage of the illness when the symptoms of the illness increase and predominate, there is deterioration and no hope of improvement, and ending in the patient's death. In your opinion, how long did the terminal, severe stage of the illness last in the case of your relative?"

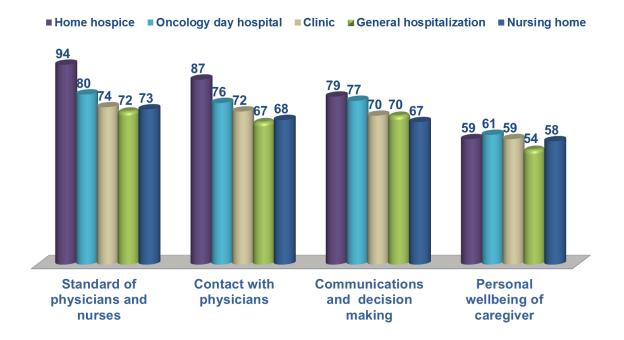
According to the reports of family members of the deceased patients, this period lasted 77 days on average (from 1 day to more than a year; median, 45; standard deviation, 108). We asked the family members what the dominant care provider (DCP) was during the severe, acute stage of illness culminating in the death of their relatives. They cited five DCPs. For more than a third of the patients (36%), the DCP at this stage was the staff in the community clinic. For another 20%, the DCP was the oncology day-hospital unit, where patients received chemotherapy and radiotherapy. For 18% the DCP was the general hospital. For 16% a nursing home where the patients were hospitalized towards the end of their lives was the DCP. A home-hospice unit was the DCP for only 10% of patients (Figure 6).

Figure 6: The Dominant Care Provider in the Final Stage of the Illness (%)



We then asked the family members a series of questions about the quality of care provided by the patient's DCP. Figure 7 presents the average score for each of the four parameters of quality of care provided by each of the five DCPs. For the first three parameters, there was a difference in the quality of care between the DCPs. Home-hospice as the DCP received the highest average score, followed by the day-hospital unit. The scores of the community clinic, general hospital and nursing home were lower. The fourth parameter – the personal wellbeing of the main family caregiver – yielded a different picture. Here, the average score was lower than for the three parameters related to direct patient care, with no differences found between the five DCPs.

Figure 7: Reported Quality of Care Average Score on CANHELP Parameters (Range 0-100) (%)



We examined which characteristics relate to the score assigned by means of multivariate regression to each of the parameters of quality of care. Controlling for age, gender and population group (Jews/non-Jews), we found that the fact that a patient died at home — as opposed to in a general hospital or nursing home - showed a significant independent relationship with higher scores on the first three parameters (the professionalism of physicians and nurses, contact with physicians, and communication and decision making), but not with the personal wellbeing of the family member who served as the main caregiver.

When the home hospice was the dominant care provider there was a significant relationship with higher scores for contact with the physician, professionalism of nurses and physicians. When the DCP was an oncology day-hospital there was a relationship with higher scores for the professionalism of nurses and physicians and communication on decision making.

Table 2: Quality of Care in Four Parameters, by Characteristics of Patients and Service Usage (Multivariate Regression)

	Contact with Physician		of Phys	Professionalism of Physicians and Nurses		Communication and Decision Making		Il Wellbeing ily Member rviewed
	В	Beta	В	Beta	В	Beta	В	Beta
Patient's gender: men (vs. women)	-2.813	064	-2.065	054	-1.498	035	-3.513	123
Patient's age (continuous low to high)	015	010	040	030	076	051	.146	.146*
Population group: Jews (vs. Arabs)	-5.832	130	-4.258	108	-4.445	101	922	031
Place of death: home (outside the home)	7.471	.165*	8.770	.220***	7.807	.177**	2.147	.072
Dominant care provider: Local clinic	11.149 -2.795	.158 051	15.579 1.058	.249 .022	4.708 1.428	.068 .026	381 -3.480	008 094
Home-hospice	691	012*	3.541	.067***	574	010	213	005
Hospital ward	7.233	.137	8.712	.186	9.344	.179	4.750	.136
Nursing home	-2.813	064	-2.065	054	-1.498	035	-3.513	123
Oncology day-hospital	015	010	040	030**	076	051**	.146	.146

*p<0.08 **p<0.05*** p<0.01

3.5 Home-Hospice Care

One of the goals of the study was to examine the extent of care provided by two home-hospice units functioning in the northern district and to check whether the quality of care they provide is distinct from that of other frameworks. To verify whether a patient received home-hospice care, we relied on two methods:

- 1) we drew the details of every patient with a recorded expenditure for home-hospice from the administrative file;
- 2) we asked family members if the patients had been treated by the home-hospice unit and whether they, the relatives, defined this source of treatment as the dominant care provider (DCP).

According to the administrative file, 19% (82 people) of the 429 entries had a recorded expense for home-hospice care, which the patients presumably received, if only briefly. The family members interviewed noted that 25% of their deceased relatives (49 out of a total of 193 patients), had been treated by home-hospice and that it had been the dominant care provider for only 10% (20 people) of the patients. For the remaining 15% (29 people), the respondents noted other DCPs even if a patient had received treatment from the home-hospice unit. Possible reasons for these numbers may be that a patient was referred to home-hospice close to death and received short-term care, or was hospitalized in a nursing home towards the end of life but received home-hospice care prior. A patient may have received home-hospice care without the knowledge of family members since the staff members of one of the units introduce themselves as providing "supportive care" so as not to arouse fear and opposition. Also, some patients apparently received

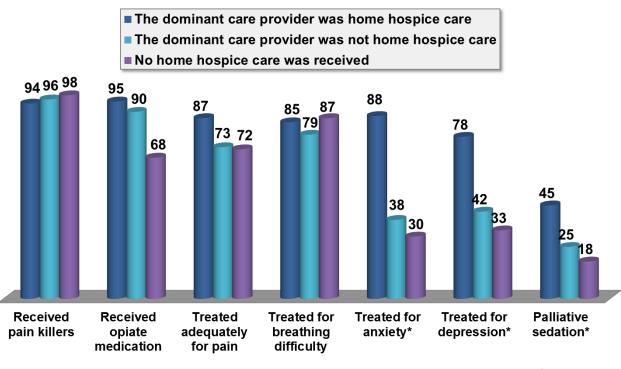
limited treatment from the home-hospice units, which did not become a significant source of care or the dominant care provider. However, there may well be additional reasons that are not fully clear to us.

To compare the quality of care received by patients treated by home-hospice with that of patients not treated by home-hospice, we created three groups based on the records of the administrative file:

- 1. Patients treated by home-hospice, whose family members described home-hospice as the DCP during the severe, terminal stage of the illness (hereafter, home-hospice/DCP)
- 2. Patients treated by home-hospice whose family members did not describe it as the DCP during the severe, terminal stage of the illness (hereafter, home-hospice/non-DCP)
- **3.** Patients not treated by home-hospice during the severe, terminal stage of the illness (hereafter, no home-hospice).

In all three groups (Figure 8), we found that most patients at the terminal stage received treatment for pain and breathing problems. A similar proportion of patients receiving home-hospice care – whether or not it was the dominant care provider – received opiate medication at the severe, final stage of illness (95% and 90% respectively), whereas only 68% of patients with no home-hospice care received opiate medication. Moreover, among the recipients of opiates – patients with homehospice/DCP received more units than those with home-hospice/non-DCP or those with no homehospice (17, 11 and 9 prescriptions respectively, not shown in Figure 8). In addition, more relatives of patients with home-hospice/DCP than those of patients with home-hospice/non DCP or those of patients with no home-hospice believed that the patient's receipt of pain-management medication had been appropriate (87%, 73% and 72% respectively). The great advantage of home-hospice as the dominant care provider was especially evident with regard to emotional symptoms. Figure 8 shows that, 88% of the family members of patients with home-hospice/DCP reported the patient received treatment for anxiety (among patients suffering from it), and 78% reported the patient received treatment for depression (among patients suffering from it) as opposed to about a third of the family members of patients in the other two groups reporting as such. Lastly, the proportion of patients receiving palliative sedation as part of their treatment was much higher among those with home-hospice/DCP than among those in the other two groups (45%, 25% and 18% respectively).

Figure 8: Comparison of Treatment of Symptoms in the Final Stage of the Illness (%)



*p<0.05

Figure 9 shows the patient's place of death and the large differences between the three groups. Most of the patients (84%) treated by home-hospice/DCP died at home compared with 38% of the patients treated by home-hospice/non-DCP, and only 26% of patients with no home-hospice.

We also examined the patterns of care for these three groups by means of a series of measures that are considered to be important principles of palliative care (Figure 9). We found that far more patients who received home-hospice care and whose relatives cited it as the DCP were treated according to the principles of palliative care compared with patients who received home-hospice/non-DCP or no home-hospice. Thus, for example, 67% of patients treated by home-hospice received explanations about their rights compare to only 10% of patients with no home-hospice; 44% of home-hospice/DCP patients had made advance provisions, such as a living will or a document stipulating their instructions compared to only 16% of patients not treated by home-hospice. In addition, the vast majority of patients treated by home-hospice/DCP (89%) died at the place of their choice compared to 30% of patients not treated by home-hospice.

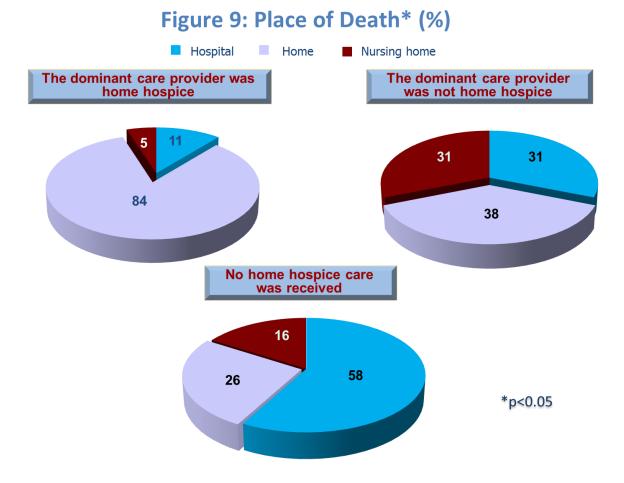
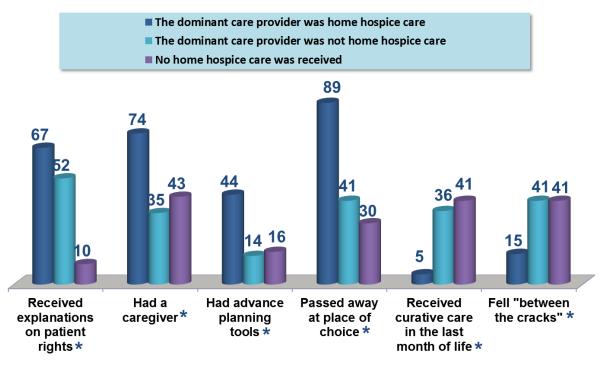


Figure 10 shows that only 5% of the patients treated by home-hospice/DCP received curative care in the last months of their lives compared with 36% of patients treated by home-hospice/non-DCP and 41% of patients with no home-hospice. We also examined whether family members felt that the patient had "fallen between the cracks" in the final period of life and, in this respect too, home-hospice as the dominant care provider showed a distinct advantage.

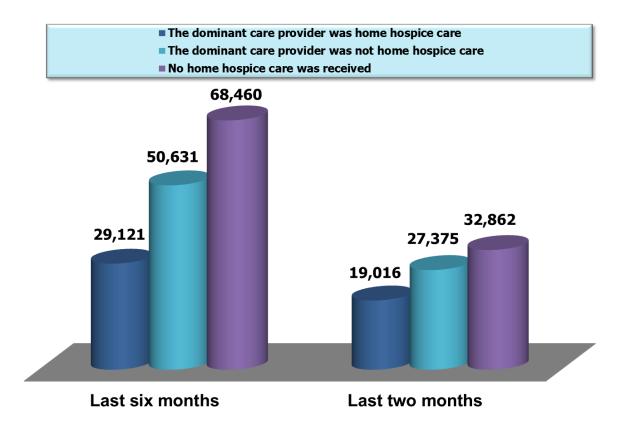
Figure 10: Palliative Care Treatment Received in the Final Stage of the Illness (%)



*p<0.05

Finally, we examined the average cost of care of patients in each of the three groups. In the last half year of life, the cost of care of patients treated by home-hospice/DCP was 15% lower than that of patients with home-hospice/non-DCP, and 26% lower than that for patients with no home-hospice. The differences between the groups widened further in the last months: during this last period, the cost of care of patients with home-hospice/DCP was 30% lower than that of patients with home-hospice/non-DCP and 42% lower than that of patients with no home-hospice.

Figure 11: Average Cost per Patient (NIS)



We found that only 24% of the expenditure on patients with home-hospice/DCP was for hospitalization, 58% was for other purchases and 18% was for medication. For patients with home-hospice/non-DCP, hospitalization accounted for 37% of the expenditure, other purchases accounted for 48%, and medication accounted for 15%. Among patients with no home-hospice, hospitalization comprised 64% of the expenditure, other purchases accounted for 28%, and medication accounted for only 8% (Figure 12).

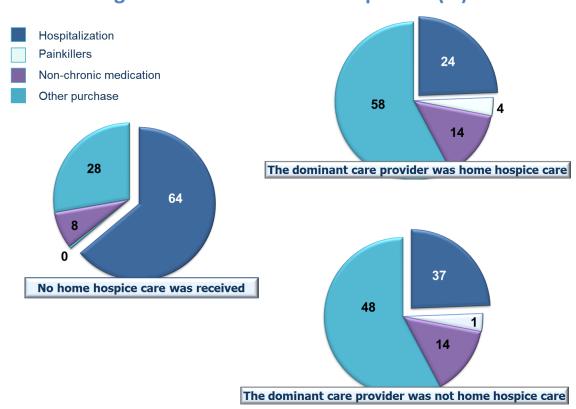


Figure 12: Distribution of Expenses (%)

4. Summary

The study yielded significant information concerning the care of patients with cancer in Israel providing the basis for improving the services and the quality of lives of the dying patients and their families.

In summary, the study findings reveal that the quality of care of patients treated by home-hospice services, which rest on the principles of the palliative approach, was higher while the cost of care was lower. However, few patients received these services. Every effort should be made to increase the number of patients treated by palliative services at the end of life to improve both the efficiency and the quality of care of these patients.

The findings were presented to decision-makers in Israel's Ministry of Health, health plans and to service providers as well as to the UJA Federation of New York and other involved organizations. They provide insight into decision-making and policymaking regarding the development of palliative services and hospice units in hospitals and the community. They serve as an informed basis for the continuing implementation of the directives of the director-general of the Ministry of Health requiring all healthcare settings to implement palliative care for patients

suffering from incurable diseases within three years. The research team continues to be involved in the development and evaluation of these processes.

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Appendix 1: Characteristics of Patients who Died of Metastasized Cancer, by Patterns of Care in the Last Half Year of Life (percentage)

	Total	Hosp. in General Hosp.	Differenti al Hosp.	Emerg ency Room	Day Hosp.	Home- Hospice	Unit for Further Care	Opiate Medication	Non- Chronic Medication
Receipt of service	Total	%87	%22	%49	%42	%19	%21	%59	%95
Gender		7001	70==	70.10	/U.=	7010	70= 1	7000	,,,,,
Male	56%	86%	24%	49%	41%	18%	18%	56%	95%
Female	44%	87%	21%	48%	43%	20%	24%	63%	96%
Age									
Up to 64	33%	87%***	27%*	55%*	57%***	26%*	23%	67%**	96%
79-65	41%	91%	24%	48%	43%	15%	24%	60%	96%
80+	26%	78%	15%	40%	19%	17%	14%	48%	95%
Population group									
Jews	73%	86%	23%	*46%	40%	21%*	21%	58%	95%
Arabs	27%	88%	19%	56%	46%	13%	19%	62%	96%
Country of origin									
Israel	44%	89%	21%	56%***	49%**	17%	22%	63%	97%
Europe/America/Australia /						240/		- 407	/
South Africa	19%	81%	23%	35%	30%	21%	16%	54%	95%
Asia/Africa	19%	90%	21%	51%	40%	17%	27%	56%	95%
Former Soviet Union after 1990	18%	82%	27%	41%	39%	24%	14%	57%	92%
Immigrant (non-Arab) Native Israeli or immigrant									
up to 1990	70%	87%	23%	47%	39%	21%	22%	56%	95%
Immigrant since 1990	30%	85%	25%	45%	42%	23%	18%	61%	93%
•	0070	0070	2070	4070	4270	2070	1070	0170	3070
Administrative council Galilee	29%	88%	25%	42%	46%	27%***	21%	63%	97%
Amakim	39%	83%	23%	53%	43%	13%	23%	55%	93%
Nazareth	32%	90%	19%	49%	36%	20%	18%	60%	97%
Physician's visit									
Non-receipt	6%	*40%**	8%*	***4%	8%***	4%**	4%**	12%***	48%***
Receipt	94%	89%	23%	51%	44%	20%	22%	62%	98%
Physician's house call									
Non-receipt	53%	*81%**	25%	44%**	43%	13%***	13%***	46%***	93%***
Receipt	47%	93%	19%	54%	40%	26%	30%	73%	99%
Nurse's house call									
Non-receipt	62%	**84%	24%	43%***	39%	13%***	14%***	52%***	93%***
Receipt	38%	91%	19%	58%	46%	29%	32%	71%	100%
General hospitalization			_						
Non-receipt	14%		**10%	26%***	33%	16%	14%	47%**	79%***
Receipt	86%		24%	52%	43%	20%	22%	61%	98%
Differential hospitalization									
Non-receipt	78%	*84%*		48%	40%	20%	22%	59%	94%*
Receipt	22%	94%		49%	48%	17%	18%	59%	99%
Lengthy hospitalization									
Non-receipt	87%	*85%	22%	50%	43%	18%	20%	59%	95%
Receipt	13%	94%	22%	41%	31%	24%	26%	59%	94%
Emergency Non-receipt	52%	*81%**	22%		34%***	16%*	16%***	52%***	92%***
Receipt	48%	93%	23%		50%	23%	26%	67%	99%
Day hospital	70 /0	JJ /0	2070		3070	20/0	20 /0	01 /0	5570
Non-receipt	58%	84%	20%	42%***		17%	18%	54%***	92%***
Receipt	42%	89%	26%	58%		22%	24%	66%	99%

	Total	Hosp. in General Hosp.	Differenti al Hosp.	Emerg ency Room	Day Hosp.	Home- Hospice	Unit for Further Care	Opiate Medication	Non- Chronic Medication
Home-hospice									
Non-receipt	81%	86%	23%	46%*	40%		19%	51%***	94%**
Receipt	19%	89%	20%	57%	48%		27%	91%	100%
Unit for further care									
Non-receipt	79%	85%	23%	45%***	40%	18%		56%***	94%**
Receipt	21%	91%	19%	61%	48%	25%		72%	100%
Imaging tests									
Non-receipt	33%	77%***	***14%	32%***	*27%**	17%	15%*	46%***	87%***
Receipt	67%	91%	26%	56%	49%	20%	23%	65%	100%
Opiate medication									
Non-receipt	41%	*82%*	22%	39%***	34%***	4%***	14%***		89%***
Receipt	59%	89%	23%	55%	47%	30%	25%		100%
Non-chronic medication									
Non-receipt	5%	*40%**	*5%	10%***	5%***	0	0	0	
Receipt	95%	89%	23%	50%	44%	20%**	22%**	62%***	