Death Education in Home Hospice Care in Japan

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Abstract / In the practice of home hospice care, death education for both patient and family is extremely important, although little information on its usefulness is available. In this study, the effects of death education under home hospice care were analyzed for 16 patients who died at home. Death education for the patient and his/her family was given at least once in each phase of care, and at least four times in total. The acceptance of death by the patients was judged according to the way they spent their remaining time, to their attitudes, and to their hope for a life after death. Fourteen of 15 patients appeared to accept their own death. An autopsy was performed in five of the 16 cases. In one case, the doctor recommended an autopsy to the family; in the other cases, it was performed in accordance with the patient’s or family’s wish. As the goal of death education in home hospice care is the acceptance of death by both patient and family, our methods of death education appear to be effective.

Résumé / Lorsqu’on dispense des soins palliatifs à domicile, il est extrêmement important que le patient et sa famille soient renseignés sur la mort et sur tous les aspects qui s’y rattachent, bien qu’il n’y ait que peu de littérature sur l’utilité de le faire. Dans cette étude nous analysons les résultats de cette formation sur la mort auprès de 16 patients qui sont décédés à la maison. Nous avons eu au moins quatre fois des conversations sur la mort avec chaque patient durant les diverses phases de la maladie. C’est à partir de la façon dont ils ont vécu leurs derniers jours, de leurs attitudes face à la mort, de leur espoir d’une autre vie que nous avons jugé s’ils acceptaient la mort. Des 15 patients, 14 semblaient accepter leur mort. Une autopsie a été pratiquée dans 5 des 216 cas. Dans un cas c’est le médecin qui l’avait recommandée à la famille, dans les 4 autres cas c’est à la demande de la famille et selon les volontés exprimées par les patients qu’elles ont été pratiquées. Dans le cadre des soins à domicile, le but de notre formation sur la mort était que le patient et sa famille puissent accepter la mort; il semblerait donc que notre méthode de préparer les patients et les familles à la mort soit efficace.

INTRODUCTION

In Japan, cancer has been the leading cause of death since 1983. In 1999, about 270,000 people or one third of all deaths were due to cancer. In 1999, 92% of deaths from cancer occurred in the general hospital, 2% in an institutional hospice or palliative care unit, and 6% at home. This trend to having death take place in institutions has meant that the general public has become isolated from dying and ignorant of methods for dealing with imminent death.

Death education in home hospice care was established as a realistic and practical method for a patient and her/his family to live out their remaining days in ways acceptable to them. It therefore involves not only medical care, but also education. Using death expected in the short term as educational material results in death education itself. However, the content must be practical and individualized, and the goals are different from those of death education in general. Although important, death education in home hospice care has not been widely studied in Japan (1). This is mainly due to doctors’ lack of understanding regarding its importance, few home hospice care services, and the difficulty of evaluating its effects objectively.

In the present study, we examine 16 terminally ill cancer patients who received home hospice care, and discuss the theory of death education. While such studies tend to be subjective and literary, we have attempted an objective analysis based on accurate data. Conversations with the patient or the family were recorded and evaluated. In 10 out of 16 cases, death conferences with the bereaved families were held to confirm whether or not our assessments were correct. Using this information, the goals of death education in home hospice care in Japan are evaluated.

CASES AND METHODS

Cases

The subjects were 16 incurable cancer patients selected from registered home hospice care. The criterion of selection was that the death education be delivered in certain ways, as will be described. All the patients died at home.
Table 1 / CASES

<table>
<thead>
<tr>
<th>Patient No.</th>
<th>Sex</th>
<th>Age</th>
<th>Primary Site</th>
<th>Duration of Home Hospice (days)</th>
<th>Family (chief caretaker)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>20</td>
<td>Bone</td>
<td>235</td>
<td>mother, father, sister</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>36</td>
<td>Stomach</td>
<td>20</td>
<td>wife, parents, 2 daughters, 2 sisters</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>43</td>
<td>Breast</td>
<td>105</td>
<td>husband, son, daughter</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>49</td>
<td>Stomach</td>
<td>44</td>
<td>husband, son, 2 daughters</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>51</td>
<td>Uterus</td>
<td>58</td>
<td>husband, sister-in-law</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>54</td>
<td>Ovary</td>
<td>104</td>
<td>husband, son, daughter, sister</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>56</td>
<td>Liver</td>
<td>24</td>
<td>wife, daughter</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>59</td>
<td>Liver</td>
<td>40</td>
<td>wife, 2 daughters, sons-in-law, granddaughter</td>
</tr>
<tr>
<td>9</td>
<td>F</td>
<td>62</td>
<td>Liver</td>
<td>96</td>
<td>husband, son</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>66</td>
<td>Pancreas</td>
<td>51</td>
<td>wife, son, daughter, mother, 3 sisters</td>
</tr>
<tr>
<td>11</td>
<td>M</td>
<td>69</td>
<td>Lung</td>
<td>54</td>
<td>wife, 2 sons</td>
</tr>
<tr>
<td>12</td>
<td>F</td>
<td>78</td>
<td>Stomach</td>
<td>28</td>
<td>daughter, grandson, granddaughter</td>
</tr>
<tr>
<td>13</td>
<td>F</td>
<td>79</td>
<td>Uterus</td>
<td>425</td>
<td>son, daughter-in-law, daughter, housekeeper</td>
</tr>
<tr>
<td>14</td>
<td>M</td>
<td>80</td>
<td>Rectum</td>
<td>292</td>
<td>wife, daughter, 2 grandsons</td>
</tr>
<tr>
<td>15</td>
<td>M</td>
<td>85</td>
<td>Prostate</td>
<td>82</td>
<td>wife, daughter and son-in-law, son and daughter-in-law</td>
</tr>
<tr>
<td>16</td>
<td>M</td>
<td>86</td>
<td>Pancreas</td>
<td>40</td>
<td>wife</td>
</tr>
</tbody>
</table>

Abbreviations: M = male, F = female

Nine patients were male and seven female. The average age was 60.8 years (range: 20–86 years). The primary cancer sites were the gastrointestinal tract in four, liver in two, pancreas in two, lung in two, ovary in one, uterus in two, breast in one, prostate in one, and bone in one. The average duration of home hospice care was 106.1 days (range: 20–425 days) (Table 1).

Death Education

Death education in home hospice care involved “truth-telling”, providing the patient and family with information regarding the disease, such as diagnosis and the fact that the disease was incurable, and the life expectancy. Death education was carried out at least four times in each case: during the introductory phase, the stable phase, the dying phase, and the bereavement phase.

During the introductory phase, the education was provided to both patient and family. The significance of their final time together at home was explained. Education covered the following areas:

- the differences in medical treatment at the hospital and in home care
- the current medical care needed and how it could be provided at home

In the stable phase, education was also given to both patient and family. The goals here were to provide support for an acceptance of death - to live with hope until death. The following points were discussed:

- the state of the disease
- the estimated time of death, with any explanation necessary
- the current medical care needed and how it could be provided at home
- nursing care of the dying (for the family only)
- introduction to similar cases and books concerning home hospice care.

In the dying phase, death education was given to the family members who were involved in the patient’s care. The aim was to allow the family to take care of the patient without medical staff involvement. The following points were discussed:

- things to note while caring for the patient
- the dying process
- how to confirm the patient’s death
- posthumous care
- grief care.

Death education after death was given to the family to manage grief. The education included the following:

- support for the family in preparing for the patient’s death
- home visits by the doctor and nurse to care for the body with the family
- final explanation of the course of the disease, including autopsy results
- a conversation with the family.

Evaluation of Death Education

To assess the effect of death education, precise documentation was used, including recorded conversations between patient, family members, and medical staff. A record of the death conference, in which the family discussed their memories, was also made.
Table 2 / "TRUTH TELLING" IN HOME HOSPICE CARE

<table>
<thead>
<tr>
<th>Patient No.</th>
<th>Diagnosis</th>
<th>Incurable State</th>
<th>Remaining Days</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Y/N Time</td>
<td>Who?</td>
<td>Y/N Time</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td>Y/N Time</td>
</tr>
<tr>
<td>2</td>
<td>N</td>
<td>Y</td>
<td>A</td>
</tr>
<tr>
<td>3</td>
<td>Y B</td>
<td>H</td>
<td>Y</td>
</tr>
<tr>
<td>4</td>
<td>Y B</td>
<td>Dr</td>
<td>Y</td>
</tr>
<tr>
<td>5</td>
<td>N</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>6</td>
<td>Y B</td>
<td>Dr</td>
<td>Y</td>
</tr>
<tr>
<td>7</td>
<td>Y B</td>
<td>D</td>
<td>Y</td>
</tr>
<tr>
<td>8</td>
<td>Y B</td>
<td>W</td>
<td>Y</td>
</tr>
<tr>
<td>9</td>
<td>Y B</td>
<td>Dr</td>
<td>Y</td>
</tr>
<tr>
<td>10</td>
<td>Y A</td>
<td>Dr</td>
<td>Y</td>
</tr>
<tr>
<td>11</td>
<td>Y B</td>
<td>Dr</td>
<td>Y</td>
</tr>
<tr>
<td>12</td>
<td>N</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>13</td>
<td>Y B</td>
<td>Dr</td>
<td>Y</td>
</tr>
<tr>
<td>14</td>
<td>Y B</td>
<td>Dr</td>
<td>Y</td>
</tr>
<tr>
<td>15</td>
<td>N</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>16</td>
<td>N</td>
<td></td>
<td>N</td>
</tr>
</tbody>
</table>

N: no Y: yes
A: after initiation of home hospice care
B: before initiation of home hospice care
Dr: doctor D: daughter H: husband W: wife

Table 3 / PATIENT'S ATTITUDE TOWARDS DEATH

<table>
<thead>
<tr>
<th>Author's Judgement</th>
<th>Living Actively In Days Remaining</th>
<th>Living Actively For The Future</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Obscure</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Exceptional case</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>16</td>
</tr>
</tbody>
</table>

"Truth-telling" was analyzed based on three points: disease diagnosis, its incurable state, and the predicted life expectancy. In one case, this analysis was not performed because the patient was mentally handicapped.

The results of death education were judged for each case by studying the process of death acceptance in the patient and family during home hospice care, and by analyzing how the death was accepted. Whether or not the deceased accepted his/her death was judged according to two criteria:

- how the patient had spent his/her last days and hours
- whether or not the deceased believed in an afterlife

The first was assessed based on the way the patient had arranged social matters, if they had made arrangements for a funeral service or grave, and if they had expressed gratitude to the bereaved. Whether or not the deceased believed in and dreamed of an afterlife was judged by what he/she said before death. For example, "I shall always be with my family even after my death", "I shall be in the same grave", and "I shall meet my family again" were considered indicative of belief in an afterlife.

The efficacy of death education was evaluated based on how the final care was performed, and whether or not the patients or families consented to an autopsy. Assessment of final care included a review of persons who attended the death, whether or not a doctor was present, and other conditions. Regarding the autopsy, who consented to the autopsy and stage of illness were analyzed.

RESULTS

"Truth-telling"

Ten patients were told the name of their illness, cancer, before home hospice care began. Five patients (Patients 2, 5, 12, 15, and 16) were not informed. Of the 10 patients who were informed, seven were told by the doctor in charge and the remaining three were told by a family member (Table 2). Eleven patients were told that their condition was incurable. Eight of these were told before initiation of home hospice care, four by the doctor in charge and four by a family member. Of the three cases told after the initiation of home hospice care, two were told by a doctor and one by a family member. In 10 cases, the time remaining to them was discussed with the patients. Except in one case, this information was provided by the author after the initiation of home hospice care.

There were many problems associated with Patient 2. The patient was a 36-year old man with stomach cancer. He was not correctly in-
formed of his illness and believed that his condition was curable. As a result, he did not want to go home from the hospital. Complying with a strong request from his family, however, his home hospice care began. Concerning “truth-telling”, there were serious discords among his family members, especially his mother and his wife. Without naming his illness, we told the patient that his condition was incurable and his remaining time was limited.

The Acceptance of Death by Patients

Based on how the patient lived during their remaining days, death was accepted by 14 patients and one (Patient 5) was unclear (Table 3). Patient 1 is omitted from the review of death education because of the patient’s lack of understanding. Judging from the hope for an afterlife, acceptance of death was observed in eight cases (Patients 2, 3, 4, 6, 10, 12, 13, and 15) and six cases were obscure. The process of acceptance was reviewed for each patient, and eight are discussed here.

Patient 2: As mentioned previously, this patient was not told the name of his disease, however, he was told that his disease was incurable. Four days before his death he said to his four-year-old child, “Papa will be disappearing,” and to his wife, “We have been married only eight years. Thank you.” Three days before his death he said to his father:

Thank you for everything, father. Let me pay my score in Heaven. Please look after by wife and son.

He was baptized on his deathbed. Although he was only 36 years old, he accepted his death, prepared for it and lived believing in an afterlife.

Patient 4: The subject was a 49-year-old woman with stomach cancer. Thirteen days before death she said:

I have made up my mind, because of the explanation I heard yesterday. However, I do not wish to be in a coffin all alone as I will feel lonely. What worries me now is that I might not be accepted in Heaven. However, Ms. Takana’s (visiting nurse) remarks have been very comforting.

Ten days before death she said:

My husband read me a book titled I Want to Die at Home (published by Hoken Dojin Sha) which was extremely inspiring.

A week before her death, all of her family members got together to talk. The following morning she said:

Everything was put in order. This must be the supreme bliss. My regret is that I shall have to leave so soon after I see my family in an ideal way.

Two days before her death she said:

I will have all your seats reserved in Heaven, so please put many handkerchiefs in my coffin.

After her death her husband remarked:

The intensity of our married life during the last six weeks of her life at home was as strong as the past 25 years. I feel sorry for her but I am convinced she must have been happy in her own way.

We judged that this patient has accepted the death actively and lived believing in an afterlife.

Patient 5: The subject was a 51-year-old woman with cancer of the uterus. At her husband’s request, she was not told that her cancer was incurable nor about her condition in general. She naturally became restless at times; she was calm when in good condition, but complained of great restlessness when in poor condition. She appeared to be stable about two weeks before her death and said, “Things will take their natural course.” Fifteen days before her death, however, she reported severe pain and her anxieties increased because she had not been well informed of her illness. Her husband strongly wished to take care of her at home but the patient was anxious because she was not in the hospital. Ten days before her death, she was moved to the hospital and remained there until two days before her death when she was taken home again. Arrangements were made one day before her death for a baptism. She was baptized a Catholic after which, according to her husband, she completely recovered her composure. In this case, the author concluded that the acceptance of death did not take place until she was baptized.

Patient 6: This was a 54-year-old woman with ovarian cancer. Twenty days before her death she said:

I have already arranged to offer my body to a hospital for medical research. I wonder if the pathological autopsy is much more significant. I do not wish to receive any medical treatment after I become unconscious... My life span is dependent on God’s will. If possible, I wish to avoid the time of my son’s entrance examination.

Nine days before death she said:

I am aware of my limited life, still I am worried about leaving my mother behind. My son will get along all right, I think. I wish to climb many mountains as I am fond of mounting climbing.

Two days before death she wrote a haiku (17-syllable poem) expressing the joy of being accepted in the heaven and her gratitude to all. The author judged that this patient too accepted death and arranged her life in her own way.
Case no. 8: The patient was a 59-year-old man with liver cancer who was discharged from the hospital. He was a company worker and had left a lot of unfinished work when he was taken to the hospital. He thought he could not manage his work in the hospital but could at home. Thus, he agreed to go home from the hospital. He handed over his job to a colleague, and settled his financial affairs. He was thoughtful to his family members especially to his wife and spent his remaining days at home in peace. The author judged that this patient accepted death. However, his attitude toward an afterlife could not be determined.

Patient 9: This was a woman, 62 years of age, with lung cancer. She was preparing for her last days at home. She read a book entitled *Kaiitei de mitouran gan kansa or Terminally Ill Cancer Patients being Cared for at Home* (Publisher: Medical Friend Co.). At the time of my first visit to her home, she said:

I do not care even if I die tomorrow providing that I can avoid the last agony.

The following is the report of a conversation between the patient and doctor three months before her death. While looking at a hand mirror, she seemed to be happy. She said:

For only a few days, I have been taking steroids and I have grown remarkably fat. If I continue like this, do you think I shall be all right for another year or so, doctor?

As your sickness is rather serious, let's make a plan for every three months to begin with. You will be quite all right for three months from now, I think. After the first three months is over, let's make a new plan for another three months.

I told her about another patient who had similar experiences.

A conversation a month and a half before her death: “Is your husband all right? “He seems to be having a hard time and I feel sorry for him.” Twenty days before her death she was worried saying, “I fear that I shall not be able to stand up and my husband likewise.” She was worried about the health of her husband and her son’s profession but she had lived out her life at home. Acceptance of death was judged to be adequate but whether or not she believed in an afterlife was not known.

Patient 10: This was an 80-year-old man with cancer of the rectum. When his doctor detected that the cancer had spread to the liver about 13 months before his death, the patient refused treatment and said, “I am 80 years old now. I have done everything I believed right and I have nothing at all to worry about or regret.” He chose to stay at home. Six months before death, he stated that he would sign the necessary documents to allow an autopsy. Four months before death he said:

I have survived 10 months since then. I am very satisfied that I chose home care.

Twenty-three days before death, stretching out three fingers, he said “I think I shall be all right for another three days.” The author judged that this patient accepted death and lived his remaining days as planned. Acceptance of death was very active. His belief in an afterlife could not be confirmed.

Patient 16: This 86-year-old man with cancer of the pancreas stated eight days before death that he thought he could live a little longer, but it was fate after all. This patient was not given adequate information regarding his disease, yet he seemed to be aware of the seriousness of his condition and accepted death his own way.

The Acceptance of Death by the Family

Generally it took some time for family members to accept the death of the patient. This acceptance took place gradually during home care and, in most cases, the family appeared to be relieved when the patient died. During the process of death acceptance by the family, there were two unusual cases, Patients 1 and 2.

In Patient 1, due to lung metastasis from an osteosarcoma, imminent death was predicted. However, the patient appeared well. His family, especially his mother, could not accept his condition. At the time of my first visit, his mother was emotional and refused to accept the information provided by my predecessor: “There is no means to cure your son’s disease.” We thought that the best way to convince this mother that her son’s death was inevitable was to show her X-rays of his chest taken every month. Four months later, with the four X-rays in front of her, she at last began to realize that her son was going to die. At that time, she regained her peace of mind and decided to care for her son, who was becoming weaker day by day, and so prepare for his death (2).

A male patient, 36 years of age with stomach cancer (Patient 2), was not given accurate information regarding his disease at the time of his return home from the hospital. As his condition worsened, the patient became anxious about not receiving hospital care. At this time, there was a dispute between his mother and his wife over...
whether to tell him the truth. We followed his wife's wishes, but also complied with his mother's wish that he not learn the name of his disease. We told him only that he was very seriously ill. The patient knew that he would die, and left a will for his children, wife and parents. He was baptized into the Christian faith in his bed and died in peace surrounded by his family. His mother, however, was troubled by the "truth-telling" even after death, and bereavement care was difficult.

Family members were with the patient at the time of death in all cases except those of Patients 4 and 9 (Table 4). In the case of Patient 3, the visiting nurse arrived at the patient's house, by coincidence, at the time the patient passed away.

DISCUSSION

Object and Person in Charge of Death Education

Education in general supports the growth and development of mankind. Death education is designed to allow individuals to choose their own way to spend their last days by providing them with issues to consider (3).

As death is inevitable in all human beings, it is important to provide education in harmony with the state of growth and development of the dying person. This involves not only medical staff, but religious leaders, philosophers, ethicists, and educators, and is an interdisciplinary field. Death education can be carried out in various places and under various circumstances (3) using many teaching materials.

In Japan, "death" is widely thought to be a taboo topic and death education in this country lags behind that in the USA and European countries. However, it was recently reported to be in a provisional curriculum in school education (4). In comparison with general death education, that given in home hospice care is entirely different since the education is designed for persons confronted with death. The object and contents, method and effects of death edu-

<table>
<thead>
<tr>
<th>Patient No.</th>
<th>Attendant Family</th>
<th>Attendant Staff</th>
<th>Circumstances At Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Parents, sister</td>
<td>None</td>
<td>Calm death in father's arms watched by his family.</td>
</tr>
<tr>
<td>2</td>
<td>Wife, parents, 2 sisters, 2 daughters</td>
<td>None</td>
<td>Death during violin music which he liked. He shed tears just before his last breath, with mouth care carried out by his seven-year-old daughter.</td>
</tr>
<tr>
<td>3</td>
<td>Husband, son, daughter</td>
<td>None</td>
<td>Almost without notice, she passed away silently while her husband and son were drinking sake at the bedside.</td>
</tr>
<tr>
<td>4</td>
<td>Husband, son, daughter</td>
<td>Nurse</td>
<td>Family gathered at the bedside due to a sudden change in breathing. No one noticed her last breath.</td>
</tr>
<tr>
<td>5</td>
<td>Husband, sister-in-law, friends</td>
<td>None</td>
<td>Despite disquietude till then, she became peaceful following a baptism at the bedside. She died calmly with her husband holding her hands.</td>
</tr>
<tr>
<td>6</td>
<td>Husband, son, daughter, sister, friends</td>
<td>None</td>
<td>Calm death during a hymn lead by her daughter who testified that she was conscious at the time of her last breath.</td>
</tr>
<tr>
<td>7</td>
<td>Wife, daughter</td>
<td>None</td>
<td>Several hours before his death, he called his daughter who rubbed his body.</td>
</tr>
<tr>
<td>8</td>
<td>Wife, daughters and their husbands, granddaughter</td>
<td>None</td>
<td>About half an hour before death, his facial expression became peaceful with a faint smile which continued until death.</td>
</tr>
<tr>
<td>9</td>
<td>Husband, son</td>
<td>Nurse</td>
<td>Visiting nurse was called due to husband's anxiety about a sudden change in breathing. Death was like falling asleep.</td>
</tr>
<tr>
<td>10</td>
<td>Wife, son, daughter, mother, 3 sisters, priest and his wife</td>
<td>None</td>
<td>Calm death watched by all family members. Daughter wanted the mother to grasp his hands which were held by the priest.</td>
</tr>
<tr>
<td>11</td>
<td>Wife, 2 sons</td>
<td>None</td>
<td>Just before his last breath, he turned off the TV by himself. Entering the room, his wife found that he had just gone.</td>
</tr>
<tr>
<td>12</td>
<td>Daughter, grandson, granddaughter</td>
<td>None</td>
<td>&quot;May I fall asleep?&quot; the patient asked her granddaughter. Shortly after, she died, but no one knew when she breathed her last.</td>
</tr>
<tr>
<td>13</td>
<td>Son, daughter-in-law, daughter, granddaughter, housekeeper</td>
<td>None</td>
<td>Just before death, the patient stared fixedly at her daughter. Then she closed her eyes and the last breath occurred soon after.</td>
</tr>
<tr>
<td>14</td>
<td>Wife, daughter, 2 grandsons</td>
<td>None</td>
<td>As soon as the respiration state changed, the family gathered at the bedside. He passed away with his hands grasped tightly by his wife.</td>
</tr>
<tr>
<td>15</td>
<td>Wife, daughter, son-in-law, son, daughter-in-law, grandson</td>
<td>None</td>
<td>Calm death surrounded by family and relatives.</td>
</tr>
<tr>
<td>16</td>
<td>Wife</td>
<td>None</td>
<td>His death was attended by his 81-year-old wife. With a gentle voice, she told us by phone that everything was over.</td>
</tr>
</tbody>
</table>
cation are, as a matter of course, different from simple education.

As family members of the patient are involved with home hospice care in Japan (1), they develop relationships with the dying patient independently. Therefore, the object of death education is not merely the dying patient but also the caretakers, the patient’s family. Death education for the family is no less important than it is for volunteers who are involved as team members in hospice care (5). Participation of the family in providing care is important in terms of manpower and for bereavement care after the patient’s death (6). The death education in home hospice reported here was performed through trial and error and we examined the way in which the deceased and the bereaved spent their remaining time together. Our death education methods involved many problems and should be further improved through daily practices. Establishment of a universal system of death education will use information collected by doctors and medical people.

**Goals of Death Education**

Deeken (3) reported 15 goals concerning death education. However, some such as the sixth goal, which was related to suicide and the 12th goal which was related to the art of death were not included in death education for home hospice care.

Among goals considered important for home hospice care were:

- the dying process (1st)
- preparation for death (2nd)
- grief education (3rd)
- elimination of fear of death (4th)
- understanding the preciousness of the remaining hours (11th).

Some other educational goals were unsuitable for home hospice care or too complex for general death education. These included:

- removal of the taboo concerned death (5th)
- matters relating to the right to know for a terminal cancer patient (7th)
- moral matters on death (8th)
- autopsy (9th)
- preparation for funeral service (10th)
- death philosophy (13th)
- religious matters (14th)
- the possibility of an afterlife (15th).

For successful home hospice care, both the patient and family must choose and support this service. Death education in home hospice care is provided for the patient and family who fulfill this criterion. However, home hospice care is not necessarily the best program for every cancer patient at the terminal stage. It was concluded that home hospice care is an exclusive right given only to patients and their families who wished to spend their remaining days together at home.

**Change in Death Education According to the Condition of the Patient**

In home hospice care, the curriculum of death education should change with the condition of the patient. It is necessary to educate the patient and family to reach the goals set for each stage of the dying process.

At the initial stage we must understand the wish of the patient correctly and, at the same time, an objective assessment of the ability of the family to provide care is important. At this stage, the significance of hospice care (7,8) and especially of its application at home should be explained in detail to the patient and family. The goal of education at the stable stage should be for the patient and family to accept death as a natural phenomenon and to understand the preciousness of the remaining days of life so that the patient can live in peace. In the final stage, the doctors and nurses should explain that death is inevitable. However, the family often told the patient the significance of life and how wonderful it was. Thus, during death education in home hospice care, the medical attendants were not merely specialists and teachers but also students.

When the patient’s condition is stable and the family is self-possessed (3), young family members or grandchildren can learn about life and death. For example, Patient 14’s grandson said, in response to a question during a TV interview:

> As my grandfather was at home I could see him getting weaker day by day. Home hospice care is hard work all right, but it is an experience that one should have once in life.

When a doctor knows that death is approaching, he/she must inform the family so that other relatives can be told and arrangements such as the funeral service, death costume, and portrait can be made. When death is imminent, education regarding the process of death, possible changes, and how to care for the patient should be provided. We explained that the medical staff could be reached at any time, so the family could feel comfortable about providing the final care alone if possible.

An important point of education at this stage was to let them know that the patient would be free from agony, but their consciousness would be retained until the last moment. Accordingly,
we reminded attendants not to make careless remarks. As reported by Segri-Swinehart (9), it is important for the family to be near the deathbed until the very last moment.

"Truth-telling"

Acceptance of death by the patient in hospice care was closely related to providing the patient with accurate information regarding their condition. To choose one’s home as a final residence, the patient must precisely understand his/her condition. The name of the disease, its stage, and the time remaining must therefore, be discussed with the patient in detail.

In Japan, in most cases, the decision whether or not to tell the patient the truth is made by the doctor or medical staff. This must be reviewed with the patient’s “right to know” (10).

Yanagida (11) outlined four points necessary to telling the truth to terminal cancer patients:

1. the information must be given clearly
2. the patient must accept the truth
3. a relationship of mutual trust must exist between the doctor and the family, including the patient
4. physical and spiritual care as well as patient support must be provided after telling the truth.

We concluded that these conditions could be directly applied to home hospice care. “Truth-telling” consists of three steps for patients with terminal cancer: naming their disease, stating that it is incurable, and giving the time remaining. Most of our patients were told the name of the disease, that it was incurable, and the time remaining. For terminal cancer patients to decide to spend their remaining days at home, the patient had to understand her/his condition.

Discussing the time remaining was more delicate and difficult than naming the disease. Selecting a suitable time to tell the patient was difficult, but the most important factors were the relationship of mutual trust between the patient and doctor, and the mental condition of the patient. We used expressions such as “Please organize a life plan on provisional supposition that your remaining days are 30 days to begin with.” The following expression was important: “I am sure that you will be fine one month from now. After that time, you will have earned extra life. You must make your life plan for another one month all over again.” This helps the patient to be comfortable and hopeful in the remaining days.

The family, however, must be accurately informed regarding the time remaining. This method of “truth-telling” differed from case to case. Generally, aged patients (70 years or more) were aware of their length of life so it was not necessary to follow to the fundamental rules in most cases. Younger patients, however, were not aware of their confrontation with death unless they were informed by doctors accurately. Furthermore, they had a lot of matters to organize before death. We therefore told such patients the truth, providing conditions were acceptable.

In home hospice care, the doctor’s and nurse’s contact time with the patient and family, especially with the patient, was extensive. During every visit, we talked with the patient and family for a least 30 minutes. Care and support after “truth-telling” were provided. With such preparation, it was possible to carry out “truth-telling” and necessary explanations in most cases. Only Patient 2 had difficulties in reference to “truth-telling”. In this case, it was difficult to comply with all of the opinions of the family within a limited time. Such situations have yet to be studied and the best way to deal with family conflicts is unknown.

Acceptance of Death as an Ultimate Goal

The ultimate goal of death education in home hospice care was the acceptance of death by the patient and family. Acceptance somewhat resembled resignation but involved active discussion and thought. Deeken (3) criticized the state of mind and psychological process of death proposed by Kübler-Ross, and added a chapter called “Stage of Expectation and Hope” to her last (5th) stage (12). According to Deeken, a human achieves tremendous growth of character in his or her last moment of life.

Hospice does not refer to a place, but a philosophy. However, a patient’s own home was reported to be the most suitable place, provided care was well arranged, for the patient to spend the remaining days with “expectation and hope”. Patients can be masters of their own homes, and are able to live with dignity. It is the easiest place for them to accept death. The authors believe the goal of home hospice care was to give a last touch of life to the patient and family, and to allow them to live out their time together with hope. The patient and family learned to live their remaining days with expectation and hope.

The authors were of opinion that, at this stage, a doctor and educator should not interfere in their lives. Instead, it was important for them to play the roles exclusive to them, roles that could not be played by anyone other than a doctor and a nurse, so that the patient and family could learn by themselves. The doctor's
role as an educator was to show the inevitable
death, estimated time of it if necessary, and how
it would occur. The simple act of counting the
number of hours remaining and of facing the
imminence of death cannot but bring about a
rapid growth of character. Acceptance of death
is nothing but a literary expression. The spiri-
tual state of the patient and family was always
unstable to the very last moment. In all the
cases studied, the authors judged the patient
had accepted death, but for each, the process of
acceptance was by no means easy.

The subject of autopsy in home hospice set-
ing, which is closely related to the acceptance
of death, has been reported previously (13).

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