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Palliative care services in The Netherlands: a descriptive study

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ABSTRACT

In this paper several types of specialized palliative care services in The Netherlands are presented. These include palliative care units in homes for the elderly, in nursing homes, in a general hospital and in an oncology clinic. In addition, a description is given of private hospices and of a home specializing in the care of terminally ill children. Furthermore, a number of other services relevant to palliative care are presented, such as professional and volunteer services for patients dying at home. Although many different types of services can be distinguished, regional distribution is not always optimal. The policy of the Dutch government on palliative care is also discussed. This policy is characterized by a strong emphasis on the further integration of palliative care in the regular health care system.

1. INTRODUCTION

The idea that high quality palliative care is a necessity for terminal patients has become increasingly evident in Western society. Palliative care includes all care aimed at the relief of the suffering of patients in the last phase of their life. In addition to management of physical symptoms, attention is paid to emotional, social and spiritual aspects. Relieving suffering is considered more important in palliative care than increasing the length of life. It is also considered essential for care in the last stage of life to fit in with, as far as possible, the individual's wishes and needs. So, patients' relatives are also actively involved in the care process and — if needed — palliative care also includes caring for relatives [1].

The reasons why palliative care is in the spotlight nowadays are not entirely clear. However, the strong interest in palliative care may be related to the fact that the number of patients dying in industrialized countries is increasing [2]. Perhaps, it is also related to the fact that we are entering a third millennium, which is connected with a new interest in spiritual aspects. The actual, often heated discussions about euthanasia may be another reason for the interest in palliative care. Some note that the demand for euthanasia would diminish markedly if a quality improvement in

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palliative care were to be achieved [3]. However, others believe that good palliative care cannot always prevent severe emotional, physical or spiritual suffering and the request for euthanasia [4]. Still, both opponents and proponents of a liberal euthanasia policy proclaim the need for palliative care of high quality.
Partly as a response to public demand for good palliative care, the Dutch government has taken important steps towards the further development of that care. For example, the Department of Public Health has assigned the development of a policy programme 'Palliative care in the terminal phase' [5] to 'ZorgOnderzoek Nederland' (ZON; in English: 'Health Research and Development Council'), a government organization. The first goal of the policy programme is further integration of palliative care into the regular health care system. The government's objective is to organize palliative care within the framework of regular (officially recognized, i.e. not private) health care organizations. Integration in the regular system is considered important, since this would improve the accessibility of palliative care for terminal patients. The second goal is improvement of care providers' knowledge and skills in palliative care. There is evidence that some care providers lack knowledge about certain aspects of palliative care, about pain relief [6], for instance. Consequently, the government regards sufficient and adequate training in palliative care and the creation of more consultation opportunities for health professionals as highly important. As a third programme goal, the broadening of insight into future trends in the supply of and demand for palliative care is being pursued by the government [5]. This is considered important since it is expected that the demand for palliative care in the terminal phase will increase enormously. As a consequence of the ageing of the population, in the next 20 years increasing numbers of people will die. In 1994, about 133,500 people died in The Netherlands; while in the year 2015, this number will be probably more than 177,000 [2] and [7]. Some of these people will die from acute disease and consequently will not make use of palliative care. However, others will make use of palliative care services. The demand for palliative care in the terminal phase is always strongly determined by death from cancer. In 1994 about 37,000 Dutch people over 55 died as a consequence of a malignant disease. In the year 2015, this number will probably grow to 45,000 [2] and [7]. Although palliative terminal care is not just restricted to final-stage cancer patients, these prognoses give strength to the belief that the need for palliative care will increase strongly.

To further develop the plans for the aforementioned policy programme 'Palliative care in the terminal phase' the ZON organization needed more information on the present state of palliative care in The Netherlands. In 1997, ZON gave The Netherlands Institute for Primary Health Care (NIVEL) an assignment for an inventory study [1]. Two research questions, which were particularly closely related to the first goal of the forenamed policy programme, were:

- what types of services are offered in The Netherlands in the field of palliative care?
- to what extent are these services integrated into the regular health care system? The 'regular care system' meant all hospitals, general practices, home

care organizations, nursing homes, homes for the elderly, health centres and other officially recognized health care organizations.

In addition, some research questions were formulated on education and support for health professionals caring for terminal patients (in connection with the second goal of the policy programme). At present, preparations are also being made for a future study which will shed light on the expected trends in palliative care (in connection with the third programme goal). However, in this article, after presenting the methods used, we limit ourselves to answering the two main research questions presented.

2. METHODS

2.1. Data collection

Because of the politically sensitive character of the research theme, the study was of short duration (4 months, from April to July 1997). Consequently, research strategies were chosen which were appropriate for collecting relevant data in a short period. Firstly, known experts in the field of palliative care (n=17), representing palliative practice or policy, were contacted by telephone. They were asked whether they were acquainted with relevant care services within the field of palliative care. Often, in addition to verbal information, these experts gave written information (e.g. internal reports) about relevant initiatives.
Next, various Dutch databases (for example, the Database on Innovative Care Projects) [8] and the catalogues of Dutch university libraries and research institutes were studied. The keywords used for the search in the databases and catalogues were: palliative care; terminal care; symptom management; pain management; pain; cancer patients; cancer; oncology; AIDS patients; AIDS. In addition, several relevant registration and member lists (e.g. of the Network Palliative Care for Terminal Patients in The Netherlands) were studied. Further, various organizations and institutions received a letter in which they were requested to send in any annual reports, internal reports or programme overviews in which palliative care services were described. These organizations or institutions were: all nine academic hospitals; the two specialized oncology clinics; the 11 comprehensive cancer centres in The Netherlands; six Dutch hospices as well as 30 other Dutch organizations specializing in the area of palliative care; all regular and private home care organizations, health centres, general hospitals and registered voluntary care organizations in the 10 largest cities in The Netherlands and all (remaining) capitals of the 12 provinces.

2.2. Inclusion criteria

Only those care services that satisfied at least one of the following two criteria were included in this inventory: the care service is directed specifically towards terminal patients; or the care service relates to a care *innovation* for terminal patients in combination with other groups of patients. For example, this might include intensive, specialized forms of home care.

2.3. Data analysis

The material gathered was analyzed to see to which specific type of care services initiatives belonged to and what their characteristics were (e.g. as regards integration into regular health care). In the initial phase of the analysis process, analytical codes concerning the different types were developed on an inductive basis, that is to say

directly derived from the material studied. Codes concerning the types of services were, for instance, 'hospice', 'palliative care unit' and 'children's home'. In addition, codes of characteristics of services (e.g. with respect to target group and collaborating institutions) were also inductively derived from the material. The coded material was then entered into a computer and analyzed by means of descriptive statistics (in SPSS5.0).

3. RESULTS

3.1. Specialized services for palliative care

Thirty-five specialized care services were identified as delivering 'total' palliative care, characterized by attention paid to physical, as well as emotional, social and spiritual care needs. Six types of services were distinguished, on the basis of the information about these 35 services. The first were *hospices*. A hospice in this study is a building outside a hospital or other institutional context, where physical as well as psychosocial and spiritual care is delivered to terminal patients. In the study period (mid 1997) six Dutch hospices existed, spread over the country. These hospices are meant for (3 to 12) terminal patients unable to die at home for medical or psychosocial reasons. The care providers in the hospices strive to make the patient feel at home, among other things by offering patients the option of furnishing a room with their favourite possessions. Relatives can stay day or night. Daily care is carried out by specialized nurses often in combination with volunteers and pastoral care personnel. Two of the hospices have their own doctors, in the other four, only the patient's personal general practitioner is in charge of medical treatment.

The second type concerns *palliative care units in homes for the elderly*. Of the ca. 1400 Dutch homes for the elderly [9], in 1997 23 had a specialized palliative care unit. These units (consisting mainly of around five beds) are for people who did not previously reside in a home for the elderly and who — often because of social circumstances — are unable to die at home. Care is carried out by nurses or carers, pastoral workers and often also by volunteers. Admission is only possible if the patient's general practitioner will be responsible for the necessary medical care. The patients have their own rooms and, in principle, the family always has access to the patient. All but one of the homes for the elderly involved are members of the network organization 'Christelijke Hospices Nederland' (CHN; Netherlands Christian Hospices). Related to the fundamentalist protestant character of the CHN, most of the member institutions are located in the Western part of the country (where relatively many fundamentalists live).

A third type is the *palliative care units in nursing homes*. There were in 1997 325 nursing homes in The Netherlands [10]. Three of these nursing homes (two in the south and one in the west of the country) had specialized units for palliative care. With respect to the size and home-like atmosphere, the palliative care units in question are largely comparable to such units in homes for the elderly (see above). One point of difference is that in nursing homes there is always a physician specializing in nursing home care who can provide medical care for the patient. Another point of difference is that nursing homes are specialized in the care of

chronic patients with complex problems, whereas elderly homes are focusing on elderly people with less complex care needs.
The fourth type is *a palliative care unit in a general hospital*. In The Netherlands, there were during the study period 105 Dutch general hospitals [11], of which only one (in Tiel) had a specialized palliative care unit. The unit was set up mid-1997 and at that time had four single rooms. Ultimately the unit will accommodate 10 patients. The target group needs to be further specified by the policy makers and caring staff involved, but is made up initially of terminal lung disease patients who cannot remain at home for medical reasons. Various disciplines share in the care: doctors, nurses, volunteers, pastoral and social workers. Together they try to create a home-like and personal atmosphere, comparable with the previously described palliative care units in homes for the elderly and nursing homes.
There is a fifth type, *a palliative care unit in a specialist oncology clinic*. There are two cancer clinics in The Netherlands, one of which (in Rotterdam) has a palliative care unit. The unit concerned has eight beds for cancer patients who need complex palliative care. There is a core team of oncologists and specialized oncology nurses. This core team works closely together with other disciplines, like pastoral and social workers and paramedics. In this specialized oncological setting, the quality of the medical–technical treatment is of primary importance. However, in this unit too, professionals strive to create a personal atmosphere and to pay attention to the 'whole person'.
The sixth type is a *medical children's home specializing in care for children with a terminal disease*. One Dutch childrens' home of this kind was found, in the east of the country (in Wezep). This children's home compares in many aspects with the hospices described earlier; in both kinds of institutions specialized palliative care is provided in a building outside the walls of a regular care institution. The big difference, however, is in the age of the target group (between 0 and 13). There is room for eight children with terminal diseases, who do not need hospital treatment, but who have no parents or social network able to care for them. The core team consists of paediatric nurses and volunteers, supported by a general practitioner and a child psychologist.

3.2. Other services relevant to palliative care

In the following, services are described that are directed at *aspects* of palliative care, and services, where it is not clear on the basis of the available data whether 'total' palliative care is delivered. These services will be discussed in this article under the umbrella term 'other services relevant to palliative care'.

Based on the available information about 119 of these 'other services', seven types are distinguished. The first includes *professional care services for terminal patients staying at home*. Nearly every Dutch citizen has a personal general practitioner who is — in principle — always more or less involved in the caring process for terminal patients staying at home. The general practitioner often works together with nurses or carers of home care organizations. In The Netherlands, there are about 125 regular professional home care organizations and about 165 private ones [12] and [13]. How

many of the general practitioners and the professional home care services have a specific focus on caring for terminal patients (among other target groups) is not clear. However, in this study, 46 services of the type known as 'professional care services for terminal patients staying at home' were identified. Activities performed within these services often involve home-care technology or other forms of complex, intensive home care.

Volunteer care services for terminal patients staying at home is the next type distinguished. In The Netherlands, there is the option in a great many places of volunteer care for dying people. According to the National Association Volunteers Terminal Care (St. VTZ), there were in 1997 more than 140 locations with volunteer organizations attending terminal patients. In this study we analyzed 15 of such services. The volunteers involved do not replace, but only support professional care givers. Volunteers are mostly active in sitting up with the patient during the night, psychosocial support of patients and relatives, light nursing and house cleaning tasks.

A third type is formed by *'almost-at-home-houses'*. Houses of this type have much in common with hospices ascribed before, as far as the home-like environment and personal attendance of patients and family are concerned. The main difference is that the core staff of an almost-at-home-house consists *entirely*of volunteers, while professional nurses (and sometimes also doctors) work in the hospices too. For complex pain and symptom management, in the almost-at-home-houses, external professionals always have to be called in. In The Netherlands, there were in 1997 three almost-at-home-houses, all situated in the west of the country and established by the 'Hospice Beweging Nederland' (The Netherlands Hospice Movement).

A fourth type concerns *nursing homes or homes for the elderly with no palliative unit, but with specific interest in the care for terminal patients*. As has been said, in The Netherlands there are about 325 Dutch nursing homes and circa 1400 homes for the elderly. The precise number of homes without a palliative care unit but with explicit attention for the care of dying people is lacking. In this study, however, 20 services belonging to this type are described. The interest in palliative care in the homes in question may be apparent, for example, from participation in projects or network organizations within the field of palliative care.

The following, fifth type is formed by *hospitals without a palliative unit, but with specific interest in the care for terminal patients*. There are about 105 general, 13 categorial and nine university hospitals in The Netherlands [11]. In the presented study there are nine hospitals described, without a specialized palliative care unit, but with a special focus on the care for the dying. The special focus is, for example, expressed by (often internal) reports on palliative care, participation in relevant projects, network organizations or concrete hospital policy. In addition, this attention can also be deduced from the fact that in some of these hospitals, specialized *palliative consulting teams or consultants* are active. The consulting teams often consist of medical and nursing personnel with specialist skills in palliative care. The team members function in an advisory role rather than in a practical supporting role. Often not only hospital personnel but also primary care professionals can call on the team.

The sixth type consists of *servicesfor* (*advanced*) *painalleviation*. There are many specialized services in The Netherlands in the area of pain alleviation for terminal patients. In a study carried out in 1992 by the CBO/Dutch Association of Anesthesiologists [14], 133 anesthesiologists indicated that they had carried out pain

relief treatments for (terminal) cancer patients in the previous year. Fifteen of the services for (advanced) pain alleviation were analyzed in this study. Determining the appropriate level of opiate medication and administering opiates via (often spinal or epidural) infusion are frequently occurring activities within these services.

The last type of the 'other services relevant to palliative care' concern *services for psychosocial support* for terminal patients. This type is about psychosocial guidance from psychologists or psychiatrists in the psychosocial departments of the two oncology clinics and a number of other hospitals in The Netherlands. In addition, the psychosocial support from patient self-help groups and comprehensive cancer centres belong to this type. There are also private institutes that offer psychosocial guidance to people with a serious illness. The exact number of relevant services is lacking, but in this study, 11 services for psychosocial support were described. Even though the support most often begins before the terminal phase, individual guidance can sometimes continue until shortly before death. Activities that are part of this type are counselling and sometimes also relaxation and meditation techniques.
In contradistinction to the specialised palliative services described earlier, the seven types of 'other services relevant to palliative care' are often not exclusively oriented to terminal patients, but, for instance, also to cancer patients or AIDS patients in general (see Table 1).

[TABLE 1]

3.3. Integration in regular care

We have also studied whether services in the area of palliative care are integrated into the regular health care system, that is to say whether they form part of regular (not-private) care organizations and fall within the responsibility of these institutions. On the basis of the material studied it can be concluded that there is total integration of specialist palliative care services into the regular care system, except in the case of the private hospices and the specialized medical children's home (see Table 2).

[TABLE 2]

Most 'other services relevant to palliative care' are integrated into regular health care as well. An exception is formed by a number of the professional home care services for terminal patients, mainly involving home care by private firms. In addition, a number of the services for psychosocial support take place under the mantle of non-regular, private institutions. A number of the volunteer home care services and the ' almost-at-home-houses' are also not integrated in regular health care (see Table 3).

[TABLE 3.]

The large degree of integration in the regular health care system is also illustrated by collaborative networks. As Table 4 shows, in all types of specialized palliative care services, various (often regular) care organizations are involved. For the 'other services relevant to palliative care' there is also much cooperation between diverse (often regular) institutions (see Table 5).

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[TABLE 4.][TABLE 5]

In addition, the extent of integration in regular health care is also illustrated by the sources of funding. More specifically, when a service is partially or totally financed by the usual, fixed reimbursements of private or non-private health insurance companies, this is an indication of its integration into the regular health care system. On the other hand, when a service is totally financed by private donations this provides an indication that the service is not integrated into regular health care. In the study presented, it was found that the specialized services for palliative care were, in most cases, partially paid for by the usual reimbursements of health insurance companies, while private donations or extra (project) reimbursement by health insurance companies were additional sources. However, this is not the case for most of the private hospices and the specialized childrens' home which are often totally dependent on private gifts and financial sources of patients.

The services described as 'other services relevant to palliative care' are often (partially or totally) funded by the usual reimbursements of health insurance.

4. Conclusions and discussion

In this study several types of specialized palliative care services were presented. Firstly, six Dutch hospices were described. Another type of specialized service includes the palliative care units in homes for the elderly. In addition, three palliative care units in nursing homes were identified. Because of their expertise in the intensive care for the elderly and the chronically sick, nursing homes are a suitable place to deliver palliative care. However, this does not, per se, have to happen within a specialized palliative care unit. Quite recently a quality protocol has been developed by the Dutch Association of Nursing Home Care for the care of terminal patients in the usual nursing home situation [15].

One palliative care unit in a general hospital and one in an oncology clinic were also described. A separate palliative care unit in a clinic or hospital may be important for patients with complex care needs. However, insight into the extent of the needs of this specific group of terminal patients does not yet exist. There is also no insight into the extent to which complex palliative care can be guaranteed in usual hospital settings in The Netherlands. Accordingly, statements about the desirability of expanding palliative care units in hospitals and clinics cannot be made on the basis of this study.

A children's home specializing in the care of terminal children has also been identified. Another inventory study [16] has shown that per year there are ~30 terminally ill children in The Netherlands who have no social network to support them. According to that study, the present (children's) hospitals are not able to deliver care to this specific group of children. The medical children's home described in our study may therefore meet a need. One problem, however, may be that this children's home will have little significance for children from other parts of the country. We should therefore reflect upon the function of other children's homes and children's hospitals.

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A number of ‘other services relevant to palliative care’ are also described, for instance including volunteer home care services and almost-at-home-houses. Volunteer care for terminal patients is still increasing in The Netherlands. Since 1997 the coordination of registered volunteer care for terminal patients has been partially funded by the government, which can be considered as an acknowledgement of the important work of volunteers.
The study presented also indicates that in The Netherlands the majority of services within the field of palliative care is integrated into the regular health care system. Still, Dutch hospices, almost-at-home-houses, a number of services for psychosocial support and many professional and volunteer home care services have a private, non-regular character. The Dutch government, however, considers close collaboration with the regular health care system as a prerequisite for (financial) governmental support [5]. Therefore, it can be expected that in the near future more and more private services will integrate into regular health care services.
As far as the types of palliative care services are concerned, there are major similarities between The Netherlands and other industrialized countries. In America, England, Spain and Belgium for example, there are also hospices and palliative care units. It is however difficult to judge whether The Netherlands is keeping pace with the other countries named. It is, for example, known that there are more than 200 hospices in England, and in The Netherlands there were six (in 1997, the study period). However England has ca. 60 million inhabitants as opposed to about 15 million in The Netherlands. In order to judge whether there are too few Dutch hospices, one would also have to take into account the possibilities of the entire health system and government health care policy. In The Netherlands, more than in most other Western countries, there is a strongly developed system of home care and general practitioner care, which may explain why the number of Dutch hospices is rather small. Also the fact that the Dutch government discourages the development of private initiatives, may be responsible for the small total number of hospices.
The distribution of palliative care services in The Netherlands seems not yet optimal. In the south and north of the country, there are almost no palliative care units in elderly homes, and in other regions, such units are seldom found in elderly homes with a non-protestant character. Partly as a result of these findings, the Dutch Ministry of Health decided in 1998 to form six ‘academic clusters’ spread over the entire country. Within each of these clusters, universities, hospitals, nursing homes and homes for the elderly, comprehensive care centres, general practitioners and other primary care providers will work together. The intention is that these clusters will not only enhance the regional and denominational distribution of these services, but will also stimulate their integration into the regular health care system.
On the basis of the study presented, some statements can be made about the main characteristics of the supply of palliative care services in The Netherlands. We want, however, to emphasize that this study was not meant and is not suitable for deriving any conclusions about the quality level of Dutch palliative care. The present, often difficult discussions about the quality of palliative care in relation to euthanasia cannot be directed on the basis of our data. It would therefore seem desirable to perform future research on the quality of palliative care and how that influences patients’ and care providers’ decisions in the last stage of life.

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In conclusion, a remark about the completeness of the study presented. As has been indicated several times in Section 3, the number of services within the category ‘ other types relevant to palliative care’ does not always reflect the actual number. We do however expect that the inventoried number of *specialized* palliative care services, like hospices and palliative care units, does reflect the actual number. This expectation is based on the fact that in the consultation round among experts and in the extensive registries of the Network Palliative Care for Terminal Patients in The Netherlands, we did not find any indications of additional specialized services.

REFERENCES

[1] A.L. Francke, A. Persoon, D. Temmink, A. Kerkstra; Palliatieve zorg in Nederland (Palliative care in The Netherlands). Een inventarisatiestudie naar palliatieve zorg, deskundigheidsbevordering en zorg voor zorgenden, NIVEL, Utrecht (1997)
[2] Rijksinstituut voor volksgezondheid en Milieu; Volksgezondheid Toekomst Verkenning (Inventory of Future Public Health). De som der delen, RIVM, Bilthoven (1997)
[3] C. Saunders;Voluntary euthanasia Palliative Med, 6 (1992), pp. 1–5
[4] M. Hurwitt; Letter to the Times The Times (1991), p. 17 October
[5] ZorgOnderzoek Nederland; Palliatieve zorg in de terminale fase (Palliative care in the terminal phase). Programmavoorstel, ZON, Rijswijk (1997)
[6] A.G. Boekema, A.C.A. Mak, A.H. Wigboldus, A. Wulferink; Pijnbestrijding bij kanker: een knelpuntenanalyse (Pain management in cancer: a problem analysis) Medisch Contact, 49 (4) (1994), pp. 128–131
[7] P.A.M. Akker, M.H.L. Van den Tits, N.M. van Kok; Leven met de dood. (Living with death). Over terminale patiënten en terminale zorg in NederlandBohn Stafleu Van Loghum, Houten/Zaventem (1994)
[8] NIVEL, Trimbos-instituut & NZi Innovatie in de zorgsector (Innovation in health care). Jaarboek 1996Uitgeverij De Tijdstroom BV, Utrecht (1996)
[9] Personal information from the national federation for elderly homes (WZF).
[10] Personal information from the association for nursing home care in The Netherlands (NVVz).
[11] Personal information from the national hospital institute (NZI).
[12] Personal information from the national association for home care (LVT).
[13] W.M.C.M. Caris-Verhallen, I.A. Miltenburg, A. Kerkstra; Aard en omvang van particuliere thuiszorgaanbieders in Nederland (Quality and quantity of private home care organisations in The Netherlands)NIVEL, Utrecht (1997)
[14] CBO/Nederlandse Vereniging voor Anesthesiologie; Project kwaliteitsbevordering anesthesiologische pijnbestrijding (Project quality improvement of anesthesiological pain management)NVA/CBO, Utrecht (1992)
[15] Reker CHM, Meerveld JHCM. Kwaliteitsprotocol kortdurende terminale zorg in verpleeghuizen (Quality protocol for short-stay terminal care in nursing homes). Utrecht: Nederlandse Vereniging voor Verpleeghuiszorg, 1995.
[16] Ipso Facto; Opvang van ernstig zieke kinderen (Care for severely ill children) Ipso Facto, Houten (1996)

TABLES

Table 1
Target groups for each type of the 'other services relevant to palliative care'

Type	The three target groups most frequently mentioned[a]	Number of services for whom the target group is mentioned[b]
Type 1		
Professional care services at home ($n=46$)[c]	Terminal patients (without any specification)	15
	Patients who need technical/complex care	12
	Somatic patients (without any specification)	11
Type 2		
Volunteer care services at home ($n=15$)	Terminal patients (without any specification)	12
	Terminal patients in a crisis situation or without an adequate social network	2
	Elderly patients	1
Type 3		
Almost-at-home-houses ($n=3$)	Terminal patients who cannot die at home	3
	(no additional target groups mentioned)	
Type 4		
Nursing homes/homes for elderly with specific interest in pall. care ($n=20$)	Terminal patients (without any specification)	9
	AIDS patients	5
	Terminal and other elderly patients	4
Type 5		
Hospitals with specific interest in pall. care ($n=9$)	Terminal patients (without any specification)	4
	Oncology patients	2
	AIDS patients	2
Type 6		
Services for (advanced) pain alleviation ($n=15$)	Patients with complex pain management	11
	Oncology patients with pain	3
	Patients with pain who need technical interventions	2
Type 7		
Services for psychosocial support ($n=11$)	Oncology patients	4
	AIDS patients	4
	Relatives	3

[a] 'Mentioned' means mentioned in the material studied.
[b] Sometimes for an initiative there was more than one target group mentioned in the material studied.
[c] ($n=$ . . .) reflects the number of inventoried services of one type.

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Table 2
Integration in regular health care system, for each type of the specialized palliative care services

	Totally integrated	Partially integrated	No integration	Number of services inventoried
Type 1 Hospices ($n=6$)	0	1	5	6
Type 2 Palliative care units in homes for elderly ($n=23$)	23	0	0	23
Type 3 Palliative care units in nursing homes ($n=3$)	3	0	0	3
Type 4 Palliative care unit in general hospital ($n=1$)	1	0	0	1
Type 5 Palliative care unit in oncology clinic ($n=1$)	1	0	0	1
Type 6 Specialized children's home ($n=1$)	0	0	1	1
Number of services inventoried	28	1	6	35

Table 3
Integration in regular health care system, for each type of the 'other services relevant to palliative care'

	Totally integrated	Partially integrated	No integration	Missing	Number of services inventoried
Type 1 Professional care services at home ($n=46$)	33	0	5	8	46
Type 2 Volunteer care services at home ($n=15$)	5	0	7	3	15
Type 3 Almost-at-home-houses ($n=3$)	0	0	3	0	3
Type 4 Nursing homes/homes for elderly with specific interest in pall. care ($n=20$)	20	0	0	0	20
Type 5 Hospitals with specific interest in pall. care ($n=9$)	9	0	0	0	9
Type 6 Services for (advanced) pain alleviation ($n=15$)	15	0	0	0	15
Type 7 Services for psychosocial support ($n=11$)	5	1	4	1	11
Number of services inventoried	87	1	19	12	119

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Table 4
Collaborating institutions and organizations, for each type of the specialized palliative care services

Type	The three institutions/organizations most frequently mentioned[a]	Number of services for which the institution/organization is mentioned[b]
Type 1	General practitioner practice	6
Hospices ($n=6$)[c]	Home care organization	2
	General or university hospital	2
Type 2	Home care organization	23
Palliative care units in homes	Christian Hospices The Netherlands	22
for elderly ($n=23$)	Nursing home	1
Type 3	Oncology clinic/hospital	2
Palliative care units in nursing	Comprehensive cancer centre	1
homes ($n=3$)	Research institute	1
Type 4	National/district association for general practitioners	1
Palliative care unit in general	Home care organization	1
hospital ($n=1$)	(no additional institution/organization mentioned)	
Type 5	University hospital	1
Palliative care unit in	Private training institute	1
oncology clinic ($n=1$)	University/research institute	1
Type 6	Home care organization	1
Specialized children's	Red Cross	1
home ($n=1$)	General hospital	1

[a] 'Mentioned' means mentioned in the material studied.
[b] Sometimes for an initiative there was more than one institution/organization mentioned in the material studied.
[c] ($n=$ ...) reflects the number of inventoried services of one type.

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Table 5
Collaborating institutions and organizations, for each type of the 'other services relevant to palliative care'

Type	The three collaboration institutions/organizations most frequently mentioned[a]	Number of services for which the institution/organization is mentioned[b]
Type 1	Home care organization	31
Professional care services at	General or university hospital	24
home ($n = 46$)[c]	General practitioner practice	11
Type 2	Volunteer organization	15
Volunteer care services	Home care organization	7
at home ($n = 15$)	General practitioner practice	2
Type 3	Volunteer organization	3
Almost-at-home-houses ($n = 3$)	General practitioner practice	3
	Home care organization	1
Type 4	Nursing home	19
Nursing homes/homes for elderly	Home for the elderly	5
with specific interest in pall.	General hospital	5
care ($n = 20$)		
Type 5	General hospital	9
Hospitals with specific interest	University hospital	3
in pall. care ($n = 9$)	(no additional institutions and	
	organizations mentioned)	
Type 6	General or university hospital	15
Services for (advanced) pain	Home care organization	8
alleviation ($n = 15$)	General practitioner practice	8
Type 7	Private institute for psychosocial support	6
Services for psychosocial	Department in hospital for psychosocial support	5
support ($n = 11$)	Comprehensive cancer centre or	5
	Dutch Cancer Foundation	

[a] 'Mentioned' means mentioned in the material studied.
[b] Sometimes for an initiative there was more than one institution/organization mentioned in the material studied.
[c] ($n = \ldots$) reflects the number of inventoried services of one type.

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