

A smooth transition towards the end of life – Illusion or Reality?

Master thesis

Erasmus University, Rotterdam

MSc. Health Economics, Policy and Law

ERASMUS UNIVERSITEIT ROTTERDAM
INSTITUUT BELEID & MANAGEMENT
GEZONDHEIDSZORG

Table of Contents

Abstract	3
Introduction	5
Methods	7
Study setting	7
Design	7
Sample	7
Methods	8
Analysis	8
Results	9
Phase 1	9
Descriptive findings	9
Transfers in the last three months of life and length of stay in the hospice	10
Phase 2	11
Transfers; too late, too early or appropriate?	11
Factors which can influence the moment of transfer	12
Discussion	14
Limitations	16
Conclusion	16
References	17

Abstract

Background

Previous research has indicated relatively short hospice admissions and high frequency of transfers in the last phase of life, which causes an enormous impact on the life of patients and relatives. In the Netherlands, limited figures on length of stay and number of transfers are available. Furthermore, the most appropriate moment to transfer patients to hospices and the factors associated with the moment of transfer have not been assessed. Therefore, it is unclear whether the introduction of the trajectory model by the Dutch government, which reflects the ambition to provide continuous end-of-life care, seems to be an illusion or reality.

Aim

1) To examine the number of transfers in the last three months of life and the length of stay in a hospice. 2) To explore what professionals define as the most appropriate moment to transfer patients to the hospice and to explore which factors influence the moment of transfer.

Study setting & Design

The study was conducted in a hospice in Rotterdam, the Netherlands. The study was performed as a two phase, sequential mixed method design.

Sample

Phase 1: Random sample of one hundred patients over 18 years of age who had been admitted in the hospice and who died between 2009 - 2011.

Phase 2: Nine professionals who had been involved with transfers of patients in the hospice or referring hospital.

Methods & Analysis

Phase 1: Retrospective review of patient files was performed to gather data on the following variables: gender, age, diagnosis, number of transfers in the last three months of life, referral source and length of stay (LOS). Descriptive statistics, Mann-Whitney tests and a Kruskal – Wallis test hasve been performed. Phase 2: Semi-structured interviews were held to acquire data on the moment of transfer, information accompanied with transfers and the awareness of the transition from life to death. Data were analyzed using thematic analysis.

Results

Phase 1: The mean number of transfers in the last three months of life was 2.0 ± 1.0 . The average LOS was 21 days (SD 29.0, median 13.0). A higher number of transfers was significantly (p<0.01) associated with referral source. LOS was not found to be associated with the number of transfers nor with referral source.

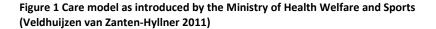
Phase 2: The most appropriate moment to transfer was defined as a transfer resulting in a length of stay between 3 weeks till 3 months and in which there was sufficient time to provide palliative care. Clinical, patient/family, physician and institutional factors were found to be associated with the moment of transfer.

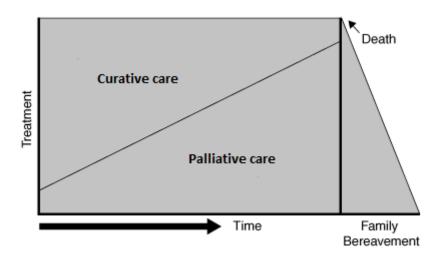
Conclusion

The majority of patients were transferred twice or more times and the length of stay was relatively short. However, it seems difficult to define the most appropriate moment to transfer on forehand since the moment of transfer is dependent on clinical, patient/family, physician and institutional factors. Therefore, continuous end-of-life care as depicted in the trajectory model still remains an ambition.

Introduction

In the Netherlands, awareness has grown that palliative care should be involved in an earlier phase in the care process since it avoids an abrupt transition from aggressive, curative treatments to palliative care (Bussemaker 2008). Therefore, one of the main ambitions of the Dutch government is to organize continuous care for these patients regardless the place where the required care is provided (Veldhuijzen van Zanten-Hyllner 2011). The Ministry of Health, Welfare and Sports (VWS) have illustrated this ambition by the adoption of the trajectory model of Lynn and Adamson, which is characterized by the gradual decline of curative care and an increase of palliative care during the course of disease (figure 1). This transition process between cure and care has been defined as a period in which the goals of care, values and insecurities of the patient are reframed (Bussemaker 2008). The Minister reasons that the ultimate goal of integrating cure and care is to enhance the ability of caregivers to anticipate on the patients' perspective of life which may change during the transition process from life to death (ibid.).





To what extent is the ambition of the Ministry of VWS an illusion or reality? Since cure and palliative care are provided in different care settings, patients with life-threatening illnesses may be transferred from one care setting to the other, even a few days before dying (van Beelen 2008). Research of Palliactief (2011) has shown that almost 60 per cent of the 210 relatives of patients who were residing in palliative care units and hospices stated that the patient was transferred in the last three months of life; twenty percent of these patients had been transferred twice and seventeen per cent experienced even more transfers. Palliactief argues that three transfers or more could indicate to problems in the organization of care, although they have not studied the reasons behind these transfers. However, the reasons for transferring patients to a hospice were studied by de Graaf et al. (2009), who found that the most frequent reported reasons for admission in the last phase of life were symptom control, complications and the absence of informal caregivers. Besides, most patients want to spend their last days of life as much as possible at home or in a 'care environment' instead of a 'cure environment' (Franke & Willems 2000). All reasons for transferring patients in their last phase

of life should in principle correspond to the general aims of palliative care, which is shortly defined as improving the quality of life of patients and their families (WHO 2011). Nevertheless, transfers are likely to cause an enormous impact on the life of patients and relatives (Klinkenberg et al. 2005:421). In these situations, patients are confronted with physical and mental distress, which stands far from the intentional goals of palliative care (van Beelen 2008). Moreover, transfers leave their mark on the professionals involved; according to a study of Niak and DeHaven (2001), specialists regard transfers as an effect of their own failure. Despite the aforementioned drawbacks, it is not always possible for patients with life-threatening illnesses to evade from transfers, since their inconstant course of disease requires various types of care arranged in different care facilities.

Bearing in mind these adverse effects, an accurate timing of transfers seems crucial. Especially in case of transfers to a hospice, because late referrals may lead to short hospice admissions in which there can be insufficient time to provide the required palliative care for the patient and family (Paratz & Flynn 2012; Waldrop & Rinfrette 2009) A Japanese study concerning late referrals to palliative care units showed that half of the studied families determined the appropriateness of the timing of the referral to a palliative care unit as late or too late (Morita et al. 2009). The results were not associated with the length of stay of the patient in the palliative care unit. In contrast, most patients and family members in a study of Kapo et al. (2005) perceived the enrollment of the patient in the hospice as correctly timed, despite the relatively short length of stay (median of 20 days). The authors suggest, as a possible clarification for this finding, that the assessment of the moment of transfer has been outweighing the overall satisfaction of the patient and family members with hospice care. Furthermore, an association was found between the perceptions concerning the timing of referral and the length of stay in the hospice; of those families who perceived the referral as too late, patients were admitted for a shorter length of stay than families who determined the referral as appropriate or too soon (Kapo et al. 2005). Miller et al. (2003) found that the probability of short hospice admissions in their study population has increased over time; although more patients were transferred to hospices, higher proportions of patients received fewer days of hospice care (Miller et al. 2003). Meta-analysis performed by Smith et al. (2012) showed that the trend of short hospice admissions has not been advantageous, since palliative care interventions alongside conventional care are generally proven to be beneficial for the quality of life of patients and caregivers.

The aforementioned studies give the general picture that patients in their last phase of life are transferred frequently, that these transfers can be burdensome for patients and that the average length of stay in hospices is often too short. These figures seems to contradict with the ambition of the Dutch Ministry to strive for early involvement of palliative care in the course of disease in order to provide continuous care. There are, to the best knowledge of the author of this article, limited recent figures available of the length of stay in hospices and the number of transfers in the last three months of life. The most recent Dutch figures that were found were from a study of NIVEL in 2006, which found an average length of stay in palliative terminal care facilities of 30 days (Mistiaen et al. 2006). Furthermore, the perceptions of professionals concerning the most optimal length of stay in hospices and the factors which may influence the moment patients are transferred to hospices have not been assessed. Therefore, the purpose of this mixed method study was twofold; it was intended to provide recent data about transfers and length of stay in one hospice and to explore the factors which influence the moment of transfer. The research questions were formulated as follows: (1) How often are patients transferred in the last three months of life and what is the length of stay in

the hospice? (2) What do professionals determine as the most appropriate moment to transfer patients to the hospice and which factors can influence the moment of transfer? The quantitative and qualitative data have been converged in order to contribute to the debate on continuous end-of-life care.

Methods

Study setting

The study was conducted in a large hospice in Rotterdam, the Netherlands, which is characterized by the great diversity in support and care it offers in the field of palliative care, varying from providing information and organizing workshops to consultation and admission. Furthermore, the hospice is an expertise centre for palliative care. The hospice offers 20 places for admission.

Design

This study was conducted as a sequential mixed method design. This study design was characterized by the subsequent collection of quantitative and qualitative data, in which the former data was used as information to guide the latter form of data collection (Creswell 2003). Therefore, the study was executed in two phases; first, a retrospective record review was performed followed by qualitative interviews with professionals. Both methods had equal priority in data collection and analysis.

Sample

In the first phase of study, the study population was defined as all patients who had been admitted in the hospice at the age of 18 or older and who died between the 1st of January 2009 and 31 December 2011. Two patients who died in the given time period were excluded by their age, resulting in a total study population of N = 601. One hundred patients were selected as study sample by performing an a-select sampling test. By using this method of sampling, every patient in the study population had an equal chance to be selected (Swanborn 2006:147).

Second, professionals for the qualitative interviews were selected by means of purposive sampling, meaning that the professionals were selected by the researcher based upon criteria that are of interest for the research question (Jupp 2006). Professionals were selected if they had been involved with transfers of patients in the role of employee of the hospice or referring hospital. Furthermore, the spread in types of functions was also included as selection criteria. The selection procedure resulted in the selection of the following professionals (N=9): a specialist, floor manager, manager, social worker, spiritual counselor from the hospice, and a specialist, two transfer nurses and a member of the Consultative Palliative Team (CPT) from the hospital.

Methods

In the first phase of study, patient files were reviewed in order to collect data on the following variables: gender, age, diagnosis, number of transfers in the last three months of life, referral source and length of stay (LOS). Data were acquired from referral letters and other related documents and correspondence which were present in the patient files.

The second phase of study, which consisted of semi-structured interviews with professionals, was conducted on the basis of an interview guide which contained questions on the moment of transfer, information accompanied with transfers and the awareness of patients concerning the transition from life to death. The questionnaire contained open questions in order to collect as much information as possible. The interviews were held in the hospice and hospital and took between thirty minutes to an hour.

Analysis

First, the representativeness of the study sample was tested with a Chi-square test for the variable gender and a Wilcoxon signed rank test for the variables age and LOS. Descriptive statistics were executed for the variables age, gender, LOS, diagnosis, referral source and number of transfers in the last three months of life. The average LOS for the study population was analyzed for the years 2009, 2010 and 2011 in order to examine a possible trend in LOS. Subsequently, two Mann-Whitney tests were performed between the variables LOS and referral source and between the number of transfers in the last three months of life and referral source in order to determine whether the differences between the variables were statistically significant. A Kruskal – Wallis test was executed to test whether the differences between LOS and the number of transfers in the last three months of life were statistically significant. The referral source was categorized in residential care and primary care. Residential care contains hospitals and nursing homes. Primary care within the context of referral source comprises G.P.'s, informal caregivers and home care as possible referrers. The analysis was performed with SPSS version 17.0.

In the second phase of study, thematic analysis of the qualitative data was performed. Thematic analysis comprises labeling of data with themes or codes in order to analyze the meaning of the themes in the acquired data (Marks and Yardley 2004). In the present study, the subjects as present in the questionnaire were elaborated in seven themes: transfers – too late, transfers – too early, most appropriate moment to transfer, awareness concerning the transition from life to death, interpretation of cure, interpretation of care and the daily practice of transfers to the hospice. These seven themes were used as codes to label the quotations in Atlas-ti. Subsequently, the quotations were analyzed per theme in order to abstract factors that potentially influence the moment patients were transferred. Finally, the factors were categorized in four groups: clinical, patient/family, physician and institutional factors. These categories were derived from the categories as applied in a study of Naik and DeHaven (2001), who distinguished three categories of predicting factors for short stay in hospices, namely; clinical, individual and institutional characteristics. In the present study we

distinguished between patient/family and physician related factors in order to illustrate the interaction between these actors.

Results

Phase 1

Descriptive findings

Five patient files of the hundred cases were absent and two patient files were incomplete. The missing data were recorded as missing values. Referral letters and related correspondence which was found in the patient files were mainly written by physicians and nurses; the letters written by physicians contained predominantly somatic information, whereas the referral letters written by nurses focused more on symptom management described from a somatic, mental and spiritual perspective. However, limited information was available with respect to the reasons for transfers; the reported reasons were in most cases formulated in standardized terms such as 'palliative care', 'shortage of informal caregivers' and 'deterioration'.

Table 1 outlines the patient characteristics. Chi-square test for gender and a Wilcoxon signed rank test for the variables age and LOS indicated that the results from the sample are representative for the study population. The sample consisted of more males (53%) than females and most patients were diagnosed with cancer (90%). Almost seventy percent (69,6%) of the patients were transferred twice or more in the last three months of life. One third of the patients had been admitted in the hospice for less than a week before they passed away. Residential care was in most cases (57) hospital care; two patients were transferred from nursing homes.

Table 1 Patient Characteristics (N = 100)

Gender		LOS in categories	
Male	53% (53)	< 1 week	33% (33)
Female	47% (47)	1 – 2 weeks	23% (23)
		2 – 3 weeks	11% (11)
Diagnosis		3 – 4 weeks	15% (15)
Cancer	90% (84)	> 4 weeks	18% (18)
Other	10% (9)		
Age		Number of transfers in last 3 months of life	
Mean (SD)	72 (11.7)	1	30.4% (28)
Range	45 - 93	2	51.1% (47)
		3	9.8% (9)
Referral source		4	5.4% (5)
Residential care	63.4% (59)	5	2.2% (2)
Primary care	36.6% (34)	6	1.1% (1)

Transfers in the last three months of life and length of stay in the hospice

On average, patients were transferred twice in the last three months of life. As depicted in figure 2, the distribution is positively skewed, although the mean, median and mode are equal. LOS has also a positively skewed distribution. After removing the extreme values (LOS>300) the average LOS of the sample was 21 days. The median and mode were respectively 13 and 3 days (figure 3). Over the years 2009, 2010 and 2011, no increase of LOS was observed.

= 2.0

= 2.0

= 2.0

= 1.0

Figure 2 Number of transfers in the last three months of life

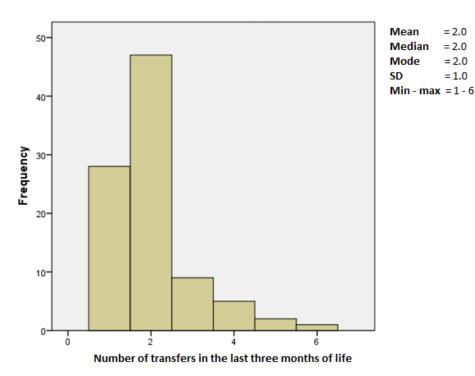
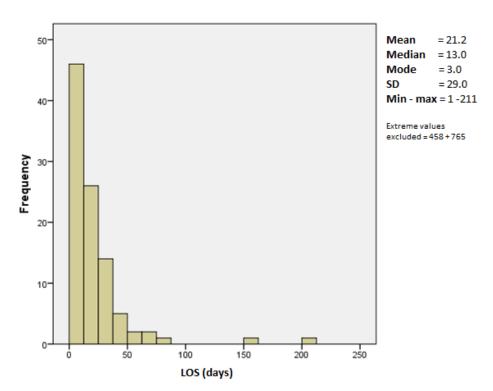


Figure 3 LOS



page 10

Mann – Whitney test have indicated that the number of transfers differed significantly for residential care and primary care (p<0.01). Figure 4 illustrates the distribution of number of transfers; patients who had been transferred from a form of residential care experienced in most cases two transfers in the last three months of life whereas most patients who were referred by the G.P., informal caregivers or home care had been transferred only once in the same period. There were no statistical significant differences found between LOS and referral source nor with LOS and number of transfers.

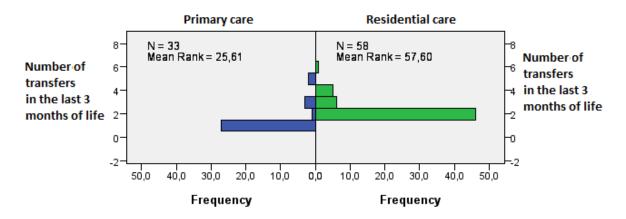
Table 2 Mann-Whitney tests

	Number of transfers and referral source	LOS and referral source
Total N	91	92
Mann – Whitney U	284.0	1012.0
Standard Error	110.7	122.7
Asymptotic Sig. (2-sided test)	0.000	0.754

Table 3 Kruskal – Wallis test – LOS and number of transfers in the last three months of life

	LOS and number of transfers
Total N	91
Chi-Square	2.6
df	5
Asymptotic Sig. (2-sided test)	0.752

Figure 4 Number of transfers in the last three months of life and referral source



Transfers; too late, too early or appropriate?

Phase 2

Professionals defined transfers as too early, too late or appropriate in terms of length of stay in the hospice and in terms of consequences for the patient and family members. In terms of length of stay, patients were transferred too late according to a physician if the patient died within two or three days after transfer. The manager of the hospice determined a transfer as too late in cases that the transfer led to a length of stay of less than two days. Concerning too early referrals, a transfer nurse

said: 'It is not an optimal situation if people stay for a half year to seven months in such a home'. Furthermore, a physician regarded transfers as too late in cases that patients were still alive after a year or one and a half year. The optimal length of stay was once determined as a minimum of three weeks and once as three months; the latter period was based upon the average length of stay mentioned at the indication which is required to be reimbursed for the care provided in the hospice. Transfers that were perceived as too late were far more common than too early transfers, according to the floor manager.

In terms of the consequences, most professionals in the hospice characterized transfers as too late in situations where there was lack of time for patients and family members to say goodbye and for professionals to make a valuable contribution to this process. The spiritual counselor said: 'In these situations, patients have too little time to feel secure and comfortable in the hospice. This also accounts for family members'. Furthermore, transfers that were perceived as too late can also be experienced by professionals as burdensome, according to the floor manager and a physician, due to the amount of work that has been invested in the transfer and the limited effect they could achieve for the patient. Transfers which led to early deaths are also in financial terms detrimental, since transfers causes an enormous investment in time and the beds in the hospice are paid for with flat payments. However, both the spiritual counselor and physician had experiences with family members who still mark the short period of time that the patient had spent in the hospice as valuable. The spiritual counselor explained this finding by saying that 'what is perceived as too late in my opinion, does not necessarily have to be late in the view of patients and family members'. In contrast, patients who were transferred too early were recognized by the spiritual counselor through their feelings of uncomfortableness; these patients were not able to identify themselves with the surrounding deaths. As a result, these patients perceived themselves as unwelcome guests. According to the manager of the hospice, patients who were transferred too early may also behave themselves as residents instead of patients dealing with their last phase of life; 'If this situation occurs, I regard the patient as transferred too early'. An optimal length of stay, which is caused by an appropriate moment to transfer the patient, was by most professionals defined as a period in which there was sufficient time for the patient and family members to grieve, to let go of life and to say goodbye.

Factors that influence the moment of transfer

From the interviews with professionals, several factors that may be associated with the moment of transfer were elicited. These factors were derived from the quotes of professionals on seven themes: transfers — too late, transfers — too early, most appropriate moment to transfer, awareness concerning the transition from life to death, interpretation of cure, interpretation of care and the daily practice of transfers to the hospice. Table 5 depicts the factors mentioned by the professionals. The factors were categorized by sort, which are clinical, patient/family, physician, and institutional factors. All factors can have a supporting and restraining effect on the moment patients will be transferred to the hospice.

Concerning the clinical factors, one of the physicians has pointed out the difficulty to determine the life expectancy of patients. The physician said: 'The unexpected course of disease may

result in transfers that seemed to be executed on the right moment although afterwards the course of disease developed differently than expected'. In the categories patient/family- and physician related factors, the awareness of patients and family members about the life expectancy and the ability of the physician to discuss this matter have a great impact on the moment patients will be transferred to the hospice. This has been illustrated by a social worker and floor manager, who both emphasized the importance of being open and honest to patients about their situation and prospects but who also acknowledged that the ability of patients to receive such information can be a restraining factor. Furthermore, a member of the CPT have pointed to the struggle of physicians to openly discuss the transition from life to death and the prospects with the patient. These physicians do not want to take away the hope of patients by clearly explaining to patients that there are no options left for treating them. On the other hand, a physician claimed that some people may also have a strong desire to be treated. For these patients, conversation on end-of-life issues can be rather confronting. The pressure on mortality rates is an example of an institutional factor that may influence the moment patients are transferred to the hospice, according to the manager of the hospice; 'I do have the impression that mortality rates are an issue for hospitals, that patients are transferred at the last moment for this reason.'

Table 5 Factors that influence the moment of transfer to the hospice

Clinical factors
Health status
Life expectancy
Available treatment options
Patient/family related factors
Awareness about the course of disease and life expectancy
Wish to stay at home as long as possible
The hope for recovery
Wish to be treated
The prospect that the hospice will be their/the patients' last home
Getting familiar with the idea and options of a hospice
Atmosphere of the hospice
Physician related factors
Treating the patient as long as possible
Keeping the hope of patients intact
Discussing the life expectancy of the patient
Institutional factors
Waiting time for the hospice
Pressure for the hospital to report low mortality rates

Discussion

In the last three months of life, 50% of the studied patients were transferred at least twice. This percentage is far more than found in the study of Palliactief (2011); only 12% of the patients studied had been transferred twice in the last three months of life. Furthermore, the finding is significantly related to residential care as referral source. It seems that in most cases, patients who experienced two transfers, were transferred from the home situation to the hospital or nursing home and, subsequently, from the hospital or nursing home to the hospice. Patients who were referred from primary care were in most cases transferred once, that is from the home situation to the hospice. Almost one-fifth of the patients were transferred three times or more; this seems as a relatively large share and thereby worthwhile for further analysis.

Concerning the moment of transfer, the professionals of the hospital and hospice defined transfers as too late, appropriate or too early transfers in a length of stay of respectively less than 3 days, 3 weeks till 3 months and 6 months till 18 months. Since the intermediary periods of 4 days till 3 weeks and 3 till 6 months were not labeled as either too late, too early or appropriate, the definition of the most appropriate moment to transfer remains unclear if measured with length of stay. According to the aforementioned definitions, the average length of stay of 21 days as found in the study sample can be defined as appropriate. In comparison with the study of NIVEL in 2006, that found an average length of stay of 30 days, the LOS found in the study population was nine days less. However, a possible decreasing trend cannot be suggested, since this trend has not been found in the researched hospice over the years 2009 till 2011. Besides, the standard deviation of 29 days indicates that transfers were not always well timed, resulting in a short but also relatively long hospice admissions. In addition, a mode of 3 have indicated that most patients were admitted for only three days in the hospice, which professionals will probably define as transfers that were timed too late. If the undefined periods of 4 days till 3 weeks and 3 till 6 months are marked as respectively too late and too early, then the majority of the patients have been transferred too late (67%). Besides, defining late transfers as a length of stay less than three weeks is in line with a study of Kapo et al. (2005), who found that family members perceived three weeks as a minimum length of stay in order to determine the transfer as correctly timed. Including the period of 3 till 6 months in the definition of too early transfers can also be justified on the basis of the indication for palliative care, which requires a life expectancy of less than three months.

In terms of the consequences transfers may bring about, it appears that too early transfers were mainly associated with patient-related consequences, such as the feelings of uncomfortableness and not feeling welcome in the hospice, whereas too late transfers also had a high impact for the professionals and management of the hospice. Surprisingly, family members, according to the professionals interviewed, may evenvalue short hospice admissions as valuable. As illustrated by the quote of the spiritual counselor, the view of professionals does not necessarily have to correspond to the view of patients and family members with regard to the moment of transfer. Nevertheless, according to the professionals, transfers were perceived as appropriately timed when there was sufficient time for professionals to support patients and their families in the last phase of life. What can be determined as sufficient time remains vague and depends on the presence or absence of the aforementioned factors. However, the factors mentioned in this article are not an

exhaustive list of possible factors influencing the moment that patients will be transferred. An example of other possible related factors is given by a study of Miller et al. (2003), who found that short hospice admissions appear to be associated with noncancer diagnoses, male gender, private insurance and the hospital as referral source. In this study, referral source was also predicted to be associated with length of stay, but this association was not statistically significant.

In the interviews held with professionals, several supporting and restraining factors that may be associated with the moment of transfer were discerned. However, some factors are related with each other which will make it difficult to be able to anticipate or influence the moment patients will be transferred. This relationship between factors is present between physician- and patient/family related factors, since these factors were derived from actors who interact and influence each other. For instance, the factor 'Physician keeps the hope of patients intact' can only exist when the patient or family member actually maintains hope for recovery. Furthermore, if the patient or family member has a persistent desire to be treated, the possibility that the physician will be stimulated to treat the patient as long as possible is greater than in cases in which the patient is fully aware of his prospects and feels comfortable with the idea of being transferred to an hospice. This stands in contrast to more objective clinical and institutional factors such as the health status, available treatments and waiting lists, which give an indication if patients are fitting the requirements for hospice admission. Thus, clinical and institutional factors provide the patient, family and physician with information that can be used to determine if the patient should be transferred to the hospice and if this is true, what moment will be most appropriate in doing so. However, the way these actors will interpret this information will be of even greater influence on the moment patients are transferred than merely the factors itself.

How does the results of this study relate to the trajectory model as introduced by the Dutch government? The trajectory model of Lynn and Adamson, as illustrated above, depicts a situation in which palliative care is introduced in an earlier phase of the disease process. As mentioned in the introduction, cure and care are provided in different care settings, which causes transfers of patients from curative settings to care-oriented settings like hospices. Therefore, it can be argued that cure is not gradually melting with care; there remains an abrupt transition from a situation dominated by cure followed by a short or long period of palliative care. This abrupt transition can be the moment patients hear that there are no options for curative treatments left, or it can be interpreted as the moment at which patients are actually transferred to the hospice. Nevertheless, in terms of the type of care provided, the model does not reflect the actual situation. Besides, the fact that this model can be interpreted in different ways indicates that the model may not achieve its overall intensions, namely that palliative care should be involved in an earlier phase in the course of the disease. The results of this study show that the majority of patients were admitted in the hospice for less than three weeks, which could indicate that early involvement of palliative care is not yet been customary. Since the Ministry of Health, Welfare and Sports still pursue the intention of integrating cure and care for means of improving end-of-life care, the focus must be shifted to the organization of our health care system in order to avoid that patients have to be transferred in their last phase of life. However, if the model is interpreted as the integration of cure and care on the level of awareness for palliative care in an earlier phase of the disease, attention must be given to the factors that influence the moment patients will be transferred. These factors are not only affecting the actual moment of transfer to the hospice, but are also applicable for the moment patients and family members are in the transition process from life to death.

Limitations

This study has several limitations which may be turned into recommendations for follow-up study. First, the scope of the study has been limited. Although the sample size was representative for the total population, the cases studied were coming from one hospice. Furthermore, the length of stay in the hospital and the period between different transfers in the last three months of life were not included in the study. Further study could incorporate these variables in order to obtain a more profound view on transfers in the last three months of life. Second, patients and family members were not included in the study. Professionals served as proxies for the patient and family members which may have led to biased outcomes. The present study did not explore whether patients and family members perceive the short hospice admissions as problematic. Therefore, including these groups will contribute to a better definition of the most appropriate moment for transfer and the factors associated with the moment of transfer. Third, the factors associated with the moment of transfer were not prioritized. Therefore, it remains unclear which factor has the most effect on the moment patients will be transferred to the hospice. Fourth, potential relationships between factors were only briefly mentioned but not analyzed in the present study. Therefore, further study is recommended to gain better insight about the priorities of and relationships between factors. These findings may be helpful for all actors involved with transfers to better anticipate on the factors in order to be able to steer the moment of transfer in the desired direction.

Conclusion

Patients with chronic diseases are in need for care that postpone the physical effects of the disease as well as care aimed at the burden of the disease approached from a more holistic view on health. In the current health care system, these different types of care, which are better known by 'cure' and 'care', are fragmented in both organizational and financial terms. Therefore, it can be necessary to transfer patients from the hospital to the hospice in order to provide them with the care they need in their last phase of life. This study was aimed to gather quantitative data of the length of stay and number of transfers in the last three months of life on the one hand, and to examine with qualitative interviews what is perceived as the most appropriate moment to transfer patients to the hospice and the factors associated with the moment of transfer on the other hand. The main finding of the quantitative study phase is that the majority of patients were transferred twice in the last three months of life and that the average length of stay of 21 days may seem appropriate, but the wide standard deviation suggests that there still existed relatively short and long hospice admissions. The qualitative data showed that, according to the health care professionals interviewed, the most appropriate moment to transfer patients to a hospice was dependent on the presence or absence of a variety of factors, that influence the moment of transfer in a restraining or supporting manner. This combination of factors determines whether the moment of transfer will be sooner or later in the course of disease, which will in turn influence the length of stay in the hospice. The most appropriate moment to transfer cannot be uniformly defined in length of stay and that the best moment to transfer is better defined in terms of its consequences. Thereby, it is impossible to determine the best moment to transfer on forehand; all definitions of optimal length of stays were determined afterwards, based upon the effects the hospice admission have had for the patient and family members. If the hospice admission was regarded as beneficial for both patient and family members, the timing of transfer was perceived as appropriate.

In general, the number of transfers at the end-of-life should be minimized, since transfers are costly and of burden for patients and family members. Especially late referrals from hospitals to hospices are associated with higher costs for society, since hospital days are more expensive than hospice admissions. Besides, hospitals are not the most appropriate environments to provide palliative care. From the perspective of 'the right care in the right place', transfers are best to be avoided. However, since transfers to hospices remain necessary for some patients in order to provide the most suitable care for the patient, attention must be given to the possibilities to reduce the burden of transfers as much as possible and to increase the awareness that earlier involvement of palliative care can be beneficial for the patient and family members. As long as the wishes and needs of patients and families stay at the centre of attention, the illusion of providing continuous care at the end-of-life may become reality at some point in time.

References

Bussemaker, M. 2008. Palliatieve zorg. Den Haag: Ministerie van Volksgezondheid, Welzijn en Sport.

Creswell, J.W. 2003. Research Design. Qualitative, Quantitative, and mixed methods approaches. California: Sage Publications, Inc.

de Graaf, E., H. M. Vrehen, C. Gamel, and S. C. C. M. Teunissen. 2009. Ziekenhuisopnames van oncologische patiënten in de palliatieve fase - een systematische literatuurreview. Nederlands Tijdschrift Voor Palliatieve Zorg 10 (3): 6-16.

Francke, A. L., and D. L. Willems. 2000. Palliatieve zorg vandaag en morgen. feiten, opvattingen en scenario's. Maarssen: Elsevier Gezondheidszorg.

Jupp, V. 2006. The SAGE Dictionary of Social Research Methods. London: SAGE Publications, Ltd.

Kapo, J., J. Harrold, J.T. Carroll, E. Rickerson, D. Casarett. 2005. Are We Referring Patients to Hospice Too Late? Patients' and Families' Opinions. Journal of Palliative Medicine 8 (3): 521-527.

Klinkenberg, M., G. Visser, M. I. Broese van Groenou, G. van der Wal, D. J. H. Deeg, and D. L. Willems. 2005. The last 3 months of life: Care, transitions and the place of death of older people. Health and Social Care in the Community 13 (5): 420-430.

Lynn, J., and D. M. Adamson. 2003. Living well at the end of life - adapting health care to serious chronic illness in old age. Washington, DC: RAND Health.

Marks, D. F., and Yardley, L. 2004. Research Methods for Clinical and Health Psychology. London: SAGE Publications, Ltd.

Miller, S. C., S. Weitzen, and B. Kinzbrunner. 2003. Factors associated with the high prevalence of short hospice stays. Journal of Palliative Medicine 6 (5): 725-736.

Mistiaen, P., L. van Ruth, A.L. Francke. 2006. Monitor Palliatieve Zorg. Rapport 2006 en bevindingen over drie jaar monitor. Utrecht: NIVEL.

Morita, T., M. Miyashita, S. Tsuneto, K. Sato, Y. Shima. 2009. Late Referrals to Palliative Care Units in Japan: Nationwide Follow-Up Survey and Effects of Palliative Care Team Involvement After the Cancer Control Act. Journal of Pain and Symptom Management 38 (2): 191-196.

Naik, A., and M. J. DeHaven. 2001. Short stays in hospice. CARING Magazine: 10-13.

Palliactief. 2011. Financiering & organisatie van palliatieve zorg: De pioniersfase voorbij? Nijmegen: Palliactief.

Paratz, E.D., and E. Flynn. 2012. Rapid death after admission to palliative care (article has not been published yet).

Smith, T.J. 2012. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care. Journal of Clinical Oncology 2012: 1-9.

Swanborn, P. G. 2006. Basisboek sociaal onderzoek. Tweede oplage ed. Amsterdam: Uitgeverij Boom.

van Beelen, A. 2008. 'Onnodige' transfers in de laatste fase. Pallium 10 (3): 16-17.

Veldhuijzen van Zanten-Hyllner, M. L. L. E. 2011. Verankering van palliatieve zorg in de praktijk. Den Haag: Ministerie van Volksgezondheid, Welzijn en Sport. Available from http://www.rijksoverheid.nl/documenten-en-publicaties/kamerstukken/2011/01/14/verankering-van-palliatieve-zorg-in-de-praktijk.html (accessed April 28, 2011).

Waldrop, D. P., and E. S. Rinfrette. 2009. Can short hospice enrollment be long enough? comparing the perspectives of hospice professionals and family caregivers. Palliative and Supportive Care(7): 37-47.

WHO. 2011. WHO definition of palliative care. in WHO [database online]. Available from http://www.who.int/cancer/palliative/definition/en/ (accessed May 24, 2011).