

Multidimensionality in Hospice care

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Abstract

Background: Palliative care is multidimensional and includes physical, psychological, social, and spiritual dimensions. Hospices provide specialist palliative care. Limited research has been performed in hospice care. Therefore, there is a lack of insight into this topic.

Objective: To gain insight into the current practices of multidimensional care provided by multidisciplinary teams in hospices and to gain insight into current hospice care in the Netherlands.

Method: A mixed methods, sequential, explanatory design was performed from January to July.

Results: It was concluded that nurses often report on all four dimensions. The multidisciplinary consults scored high on all dimensions and the spiritual dimension requires more attention from all disciplines. Participants in focus groups said that more attention was paid to multidimensionality than that which was found in patient records; however, this attention was not always reported. Interdisciplinary teams are desirable when all disciplines are responsible for attending to each of the dimensions.

Conclusions: Multidimensional care is not always reflected in patient records. The spiritual dimension is lacking, because it is considered a privacy issue.

Structure is necessary to provide care according the steps of clinical reasoning, and to give attention to all dimensions. This structure must fit into hospice care and the organisation to be supportive. Most hospices employ multidisciplinary teams; however, interdisciplinary consults are lacking. Education is required to gain the competencies necessary to give palliative care.

Recommendations: To achieve data saturation, more research is needed. There is much gained when hospice facilities start working together with all disciplines present during MDC. Also, more structured is needed in reporting methods. Care providers that use structured methods can teach this to others. Furthermore, attention must be given to the education levels of these professionals to provide a high standard of care and develop competencies in clinical reasoning and spiritual care.

Keywords: Multidimensionality, Hospice care, Palliative care

INTRODUCTION

Worldwide, 20.4 million people are in need of palliative care and 94% of these people are adult patients. However, only 10% of that need is currently being met (1). In 2013 in the Netherlands 80 % of expected deaths consisted of patients who were critically ill and had life expectancies of three months or less (2,3). These patients could benefit from palliative and hospice care during the trajectory of their illnesses.

According to the World Health Organisation (WHO) the definition of palliative care is:

“An approach that improves the quality of life of patients and their families, facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” (4)

Palliative care has different stages differentiating the aims of palliative care. In the early palliative phase, treatment and care is illness directed, aiming to prolong life by diminishing the illness. When the illness advances, the focus shifts to managing the symptoms. These symptoms can be caused by or expressed through physical, psychological, social, and/or spiritual grounds (5,6). When death is imminent, in the last two weeks to the last 48 hours of life, care and treatment aim to provide comfort and optimize the quality of dying.

Palliative care is an overall concept, whereas hospice care is specialised palliative care. Hospice care focusses on enhancing the quality of life, death, and bereavement, is multidimensional and is for patients nearing the end of life and their families (7).

To provide high quality palliative care, healthcare professionals require a clinical reasoning process. Clinical reasoning is a process of thought, an organisation of ideas, and an exploration of experiences that enables professional judgement. This process consists of four steps: signalling and analysing, following, intervening (medical and not medical), and evaluating (10). This methodical process is carefully documented in patient records. This enables health care professionals to render the care that is required and to document care (1).

Central to multidimensional care is a multidisciplinary team that includes a multidisciplinary consult (MDC); an MDC consists of at least nurses, a physician, and a spiritual counsellor. Care in hospice facilities is complemented with volunteers (5,8,9).

Though hospice care is a relatively new concept in the Netherlands, it has become a frequently selected place to receive palliative care for patients with life expectancies of three months or less. In the Netherlands in 2014 there were 310 hospice facilities, 21 of these hospices were members of the Association of Hospice Care Holland (AHCH) (12).

In the Netherlands, little is known about multidimensional care in hospices because limited studies have been performed on hospice care . From an exploration of the current literature,

preliminary conclusions can be drawn. For example, it can be concluded that the quality of hospice care differs between facilities (5). Due to the increasing proportion of elderly people, people with comorbidities, and people with life limiting diseases, hospice care is growing. As consumerism increases globally, it is important that specialised care be delivered by a multidisciplinary team. Nurses have a vital role within the team because they provide patient care around the clock (1).

Due to a lack of insight into hospice care, a large exploratory study has currently been established in hospice facilities in the Netherlands. The study discussed in this article is part of a larger study.

The aims of this study were to investigate the current practices of multidimensional care provided by multidisciplinary teams in hospice facilities and to obtain insight into current hospice care to ameliorate hospice care in the Netherlands.

The primary research question of this study was: How is multidimensional care provided by a multidisciplinary team to adult patients in the phase of symptom management who are admitted to hospice facilities in the Netherlands?

Two sub questions were formulated to answer this research question:

1. How are the four dimensions (physical, psychological, social, and spiritual) reported by members of the multidisciplinary team in patient records?
2. How do members of the multidisciplinary team reflect on multidimensional care in their daily hospice care?

METHODS

Design

A mixed methods study with a sequential explanatory design consisting of two phases was performed from January to July 2015. In the first phase, the quantitative data were collected from file research in 12 hospices across the Netherlands. In each hospice, three records were studied from deceased adult patients in January, July, and November of 2014. This quantitative component preceded the qualitative component (13).

Focus group interviews were performed in the second phase with members of multidisciplinary teams in four hospices to investigate the accuracy of documentation in patient records, because research has shown that the precision of documentation can be improved (11). The focus groups were also held to assess the differences and similarities between what happens in actual practice and what is recorded in the records, to gain a broader perspective on multidimensional care. The combination of quantitative and qualitative data collection enhanced data-richness. The analysis of the quantitative data offered a general understanding of how hospice care was provided by the multidimensional team. The qualitative data from the focus groups enhanced and refined the understanding of

the data that was found in the quantitative part of the study, by exploring the participants views on providing care in a multidimensional team (11,14-18).

Population

Records were included from patients who had a minimal period of admittance of two weeks and a maximum period of three months. The two week period was chosen to focus on the phase of symptom management. When more than one record was eligible within the timeframe of that month, one of them was selected randomly by the researcher. Participants included in the focus groups were nurses, physicians, and spiritual counsellors as these are the main stakeholders in hospice care; a minimum of four participants were included in each focus group.

Quantitative phase

The primary outcome was multidimensionality. The steps of clinical reasoning were the second outcome. To assess these outcomes in a structured manner, a self-designed instrument (Appendix 1) was used that enabled measurement at an individual level and in the MDC (5,10). Face validity was assessed through the use of the care module 'palliative care'. A group of palliative care experts assessed the feasibility of this instrument. Equivalence was assessed by establishing the extent to which two independent observers agreed on the scoring (13,18).

The instrument, measuring multidimensionality was used to score reports about the different dimensions within the steps of clinical reasoning for each discipline. For example, when a report was written by a nurse about a patients experienced fatigue, this could be scored within the physical dimension as well as the psychological dimension. When the symptom was first mentioned, this was scored in the signalling step of clinical reasoning. Further mention of the symptom fell under 'following' or 'evaluating'. When the MDC received separate documentation, this was scored as MDC. When this was not the case, it was scored within the discipline that was doing the reporting.

Qualitative phase

To select the hospice facilities for the focus groups, they were ranked according to their multidimensionality scores, based on the quantitative data; a high scoring, a low scoring, and an average scoring hospice were selected. The ranking was based on the amount of reports on multidimensionality. In addition to the ranking, a number of other items were considered when selecting hospice facilities for focus groups, such as the hospices organisational structure (three hospices, one facility with a different organisational structure), the dispersion across the Netherlands, and whether they were old or new and rural or urban. The primary

outcome was to gain a better understanding of the quantitative data and to compare this data with actual practice.

Semi-structured interviews were performed in the focus groups. The starting points of these interviews were based on the average scores and were compared to the scores of that particular hospice. Each focus group consisted of a minimum of four healthcare professionals (14,15,17,19) and was conducted in the presence of a spiritual counsellor and one to four nurses. Unfortunately, two focus groups were conducted without the presence of a physician. Reliability was enhanced in terms of stability, equivalence, and internal consistency. Stability was reached due to homogeneity in group composition, equivalence was reached by having a single team perform each of the focus groups, and internal consistency was reached by having two researchers analyze the transcripts together. Validity was established by factual accuracy of the account by one assistant-moderator and by speaking in the language of the participants during the focus group. The focus groups were audio-taped and field notes were taken by the assistant moderator (14-18). After each focus group, the content was discussed by the moderator (EG) and the assistant moderator (MK).

Data analysis

Descriptive statistics were employed for the analysis of the results of the file study, using the statistical program SPSS, version 20 (IBM Corporation, UK) (20, 21).

Focus groups were transcribed in a thematic sense, because the themes were already very clear. This clarity enabled data reduction into categories, which were organised to make a comparison, determine relevance, and draw conclusions (14,15,17,22,24).

Results

Characteristics of respondents

Twelve hospice facilities were included in the file study. These hospices were dispersed nationwide, in characteristics and differentiated by organizational differences and whether they were old or new and urban or rural. The number of beds in each hospice ranged from five to ten and the number of patients admitted in 2014 ranged from 45 to 126. Ten hospices worked with their own physicians and two worked with general practitioners. On average there were thirteen nurses employed by the hospice facilities with different educational levels. A spiritual counsellor facilitated each of the twelve hospices (Table 1).

Quantitative phase

Records from 36 patients were selected, 23 (64%) male, mean age 70. The average duration of their hospice stay was 42 days.

Disciplines

There was a large difference in the amount of reporting within the different disciplines. As shown in Figure 1, nurses reported 76%, physicians reported 15%, the MDC reported 8%, and spiritual counsellors reported 2% of the total of reports.

Multidimensionality

Although nurses mostly reported physical problems (62%), all dimensions were present in their overall reports; physicians also reported primarily on physical problems (70%). The reports of spiritual counsellors focussed on the spiritual dimension as well as the social dimension, and the reports from the MDC varied in multidimensionality (physical 48%, psychological 21%, social 15%, spiritual 16%). An overview of all dimensions and professions is provided in Table 2.

Clinical reasoning

Nurses mostly signal (10%) problems and symptoms and follow (62%) these during admission (Table 3). The reports of physicians focussed on problems in the physical dimension (35%), and spiritual counsellors' reports focussed on signalling new problems. Finally, all of the steps of clinical reasoning were reflected by reports of the MDC. However, most of the attention was paid to signalling new problems and following these problems during hospitalization. Reports also described interventions and the evaluation of the effects of interventions.

Qualitative phase

Disciplines

All focus groups acknowledged the differences in the amount of reports by the different professionals. Nurses are the major source of reports in all hospices. In addition, spiritual counsellors reflected that reporting was a no go area, all content of patients' discussions should be confidential. Therefore, they report nothing at all. However, being part of the multidisciplinary team and responsible for the reports of the work, reporting would enable all team members to reflect on problems detected and followed. Nurses found that physicians have a leading role in the team, which can work as a strength but also as a weakness when dealing with multiple physicians. This is especially apparent in MDCs. Physicians who joined the focus groups could relate to this sentiment. In two hospices the spiritual counsellor was not present at the MDC and in one hospice his input was missed. The overall conclusion from the professionals was that they work in a multidisciplinary manner, but they lack interdisciplinary collaboration.

Multidimensionality

Professionals stated that there is more attention given to all the dimensions, then what is reflected in the records. One nurse said: *'the physical dimension is more concrete than other*

dimensions. That is way the reports mostly are about the physical dimension even though the underlying issue can be psychological.' Nurses and physicians all said that it is their responsibility to provide care in a multidimensional way; however, they said that it takes courage to ask the right questions. Nurses said education and working experience can create this courage. Although most physicians attempted to take a holistic approach, most reports were about the physical dimension. The physicians in the focus groups agree with the findings yet, they agree that there is more attention given to the other dimensions than what is reflected in the file research. However, the physical dimension is seen as the main problem by nurses and physicians. The reason there is a large dispersion among the psychological, spiritual, and social dimensions between groups is that these dimensions are intertwined with each other.

All disciplines agreed that there is a privacy issue to consider and that reports about spirituality are not always recorded. One spiritual counsellor said: *'I consider it of great importance that patients can talk about whatever they want in confidence. I consider that a sanctuary'*. Although spirituality and religion were often considered similar by spiritual counsellors, when probed they acknowledge that the two concepts are different. Spiritual counsellors saw the dimensions as a shared responsibility with the other disciplines and all of the spiritual counsellors said: *'I am not a practitioner, but I am a follower.'* All disciplines agreed that spiritual counselling is an intervention; however, other disciplines miss the reports from the spiritual counsellor. All disciplines agreed that there is something to gain from spiritual counselling and nurses and physicians think that it might be helpful for their own provision of care for patients. In MDCs there was a more equal dispersion of the dimensions. One physician stated: *'Every discipline brings their own core. This enables a better view of the patient and provides better care'*.

Clinical reasoning

Both nurses and physicians conclude that evaluation requires further attention. In addition, more attention must be given to documenting the steps to ensure continuity in the care that is provided. In each focus group it was said that evaluation does happen, but it is not always reported. The main reason for this underreporting is the lack of structure in evaluation method. Sometimes evaluation happens ad hoc and it is not reported afterwards. The steps of clinical reasoning are more distinct in the MDC. Professionals in the focus groups say that there is need for a fixed structure, which helps them to go through all the dimensions and all the steps of clinical reasoning. Although structure may be helpful, disciplines also said that it can have a reverse effect when it is not fitted with hospice care and the organisation.

Discussion

Integration of results

Hospice care consists of multidimensional care, which should be a part of the daily care in hospice facilities. The inference that emerged from this mixed methods study was that multidimensionality received more attention from the multidisciplinary team than is reflected in patient records. The WHO-definition of palliative care also includes this multidimensional approach (4). All disciplines agree that care needs to be provided in a multidimensional manner. Data from the focus groups indicates that all disciplines were aware of the fact that symptoms may often be expressed physically; however, another dimension may be the underlying cause (5,6). They also thought that it is their responsibility to explore all the dimensions. Nurses said the ability to explore these dimensions depends on education and working experience.

Results from the quantitative part of the study showed that attention to the spiritual dimension is lacking. A reason for this is the incorrect use of terminology; the terms spirituality and religion are often used interchangeably. Spirituality can be defined as a personal search for meaning and purpose, whereas religion is more about shared beliefs, traditions, and rituals (24, 25). Previous research shows that the spiritual needs of 70% of cancer patients are minimally supported or not at all by professionals (26). Multiple studies have shown that patients expect this type of care from a multidisciplinary team, but not from spiritual counsellors (26, 27). Studies have also shown that patients at the end of life who receive spiritual care experience better quality of life, are less prone to choose aggressive treatments, and are more likely to enter hospice and attention for spirituality is cost-effective (27). Also, it is of equal importance that spiritual care is documented, even though this is difficult to document (24, 26). Data from focus groups show that spiritual counsellors had trouble reporting, due to a privacy issue. However, nurses and physicians said that they missed reports from the spiritual counsellor and thought this may lead to an increased awareness amongst them. There needs to be permeable boundaries between professionals to function as a multidisciplinary team (27).

A multidisciplinary team is a prerequisite for the provision of multidimensional care and hospice care (1, 28, 29). To maintain high standards of care it is necessary for the multidisciplinary team to share professional roles, expertise, and decision-making (28). The risk of a team that is composed of multiple disciplines is that they are all individuals working for the patient instead of working together as one team with the patient in an interdisciplinary manner (29). An interdisciplinary team works together and shares knowledge, expertise, and skills to impact patient care (29). One physician said that she would like to see the team working towards a more interdisciplinary method of collaboration. This way the team can view the patient from different angles to provide the best possible care (1).

The steps of clinical reasoning are used as a structure to work together as an interdisciplinary team. This methodical way of working is supported by intuition and knowledge from working experience (10, 30). This was also mentioned by nurses in the focus groups. Nevertheless, patient records show that within the steps of clinical reasoning, more attention must be given to evaluation (10). In all hospice facilities this is the lowest scoring step. A conclusion from the focus groups is that there is a need for more structure. All disciplines said that they would evaluate more when structure is offered. However, it is important that the structure fits with the hospice and the organisation; otherwise this effect is reversed.

Strengths and limitations

Broad insight into the current practices of multidimensional care in hospice facilities was gained through the mixed-methods approach. The combination of quantitative and qualitative data collection provided rich in-depth exploration of the current practices in hospice facilities. This is one of the strengths of this study. Another strength is the sample of hospice facilities that were included. In total, a third of the hospice facilities were joined with the AHCH at the time they were included. Although, it was not possible to obtain a random sample, the facilities were chosen to give a national dispersion of hospice care and to create a spread in the characteristics of the hospices. This provided a good representation of hospice care in the Netherlands.

A limitation of the quantitative phase is the number of records that were analysed. Therefore, caution needs to be rendered when drawing conclusions. Despite this limitation, the records do represent an average of one year, due to the inclusion of records from specific time periods. A limitation within the qualitative phase is that the participants of the focus groups may have been prone to providing socially desirable answers. Selection bias is another potential concern, because it is possible only participants with affinity to the discussion about dimensions joined the focus groups. A physician was absent from half of a focus groups, which is also a limitation within the qualitative phase. In one focus group the physician was replaced by the director of the hospice. This led to believe that the average opinion was captured by the focus groups. Finally, data saturation was not achieved.

Conclusion

This study sought to investigate the current practices of multidimensional care provided by multidisciplinary teams in hospice facilities and to identify strengths and weaknesses of current hospice care to ameliorate hospice care in the Netherlands. From the quantitative phase, it was concluded that nurses often report on all four dimensions, and the MDCs scored high in multidimensionality. Alternatively, the spiritual dimension needs more attention

from all disciplines. In the qualitative phase, participants in focus groups said that all disciplines pay more attention to multidimensionality than what is reflected in patient records. Within the steps of clinical reasoning, all participants of the focus groups said that they need more structure to conduct evaluations. Most hospices claim to work in a multidisciplinary manner; however, interdisciplinary teamwork is still a challenge.

Recommendations

Despite these results, questions remain. This research was of an explanatory nature. More research is needed to make conclusions about associations between multidimensionality and the quality of care. Also, data saturation was not fully achieved. Therefore, additional focus groups can be performed. Nevertheless, there are a number of recommendations. Most hospices require more structured methods for reporting and maintaining records, both in the four dimensions and in the steps of clinical reasoning. Some of the included hospice facilities have unique structures and it would be useful for them to learn from each other. However, the use of these structures can be further developed.

Hospices should have a clear definition of the spiritual dimension for all disciplines, as this makes the dimension more concrete. Research has shown that patients consider this dimension important. There is much gained when hospice facilities start working in an interdisciplinary manner with all disciplines present during MDC. Attention also must be given to the educational level of the professionals in hospice facilities. To give a high standard of care education can help develop competencies for clinical reasoning as well as in developing skills for providing spiritual care.

Figure 1 Total of reports of all disciplines

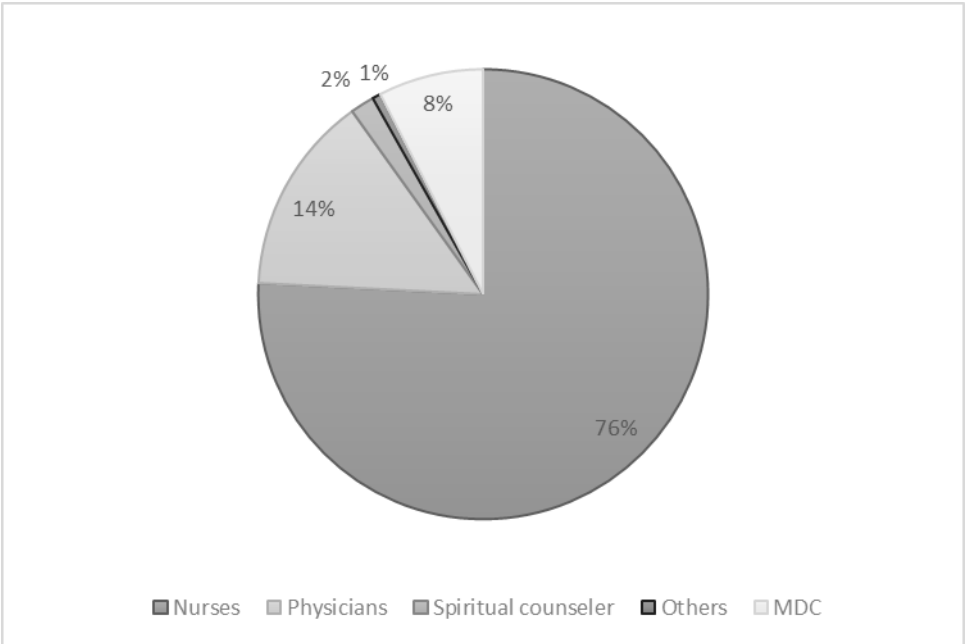


Table 1 Basic characteristics from hospices

Hospice	number of beds	number of patients 2014	number of nurses	Educational level	number of physicians	spiritual counsellor
1	7	64	15	-Nurse assistants -Registered nurses -Academically schooled nurses	14	1
2	10	84	15	-Nurse assistants -Registered nurses	2	1
3	6	62	10	-Nurse assistants -Registered nurses	General practitioners (from patients)	1
4	10	82	16	-Nurse assistants -Registered nurses -Nurse practitioner	2	1
5	5	65	17	-Nurse assistants -Registered nurses	3	1
6	5-7	77	10	-Registered nurses	10 general practitioners	On call
7	7	87	14	-Nurse assistants -Registered nurses	2	On call
8	11	126	17	-Registered nurses	1	2
9	10	76	13	-Nurse assistants -Registered nurses	1	1
10	6	45	7	-Registered nurses	1	1
11	10	98	11	-Registered nurses	2	2
12	8	103	10	-Registered Nurses	3	1

Table 2 Multidimensionality

	Nurses % (n)	Physicians % (n)	Spiritual counsellor % (n)	Others % (n)	MDC % (n)
Physical	62 (5456)	70 (1175)	7 (14)	11 (8)	48 (424)
Psychological	15 (1286)	15 (263)	18 (35)	42 (29)	21 (181)
Social	19 (1642)	9 (147)	38 (76)	16 (11)	15 (136)
Spiritual	5 (439)	5 (85)	37 (73)	30 (21)	16 (140)

Table 3 Steps of clinical reasoning

	Nurses % (n)	Physicians % (n)	Spiritual counsellor % (n)	Others % (n)	MDC % (n)
Signalling	10 (872)	27 (448)	60 (119)	35 (34)	32 (284)
Following	62 (5459)	35 (581)	39 (77)	28 (27)	37 (329)
Intervention medicaments	17 (1474)	23 (378)	0.54 (1)	0 (0)	12 (103)
Intervention non- medicaments	8 (686)	10 (160)	1 (2)	1 (1)	7 (62)
Evaluating	4 (332)	6 (103)	0 (0)	35 (7)	12 (103)

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Appendix 1: Instrument Quantitative phase.

		Physical		Psychological		Social		Spiritual	
		Diseaserelated	Functional	Emotional	Cognitive	Role patiënt In environment	Presence caregivers	Active participation religion	Existential questions
Nurse	Signaling								
	Following								
	Intervention medicine								
	Non-farma- ceutical intervention								
	Evaluate								
Physician	Signaling								
	Following								
	Intervention medicine								
	Non-farma- ceutical intervention								
	Evaluate								
Spiritual	Signaling								

counseler	Following								
	Intervention medicine								
	Non-farma- ceutical intervention								
	Evaluate								
Others	Signaling								
	Following								
	Intervention medicine								
	Non-farma- ceutical intervention								
	Evaluate								
MDC	Signaling								
	Following								
	Intervention medicine								
	Non-farma- ceutical intervention								
	Evaluate								

Instruments									
Good examples									

