Facilities for Palliative Care: Patterns and Contrasts

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ABSTRACT

**Background and aim** – Palliative care consists of a multitude of factors, such as psychological and spiritual, in addition to or integrated with nursing and facility management. Stewart, Teno, Patrick, & Lynn (1999) have developed a framework that helps understand how structure and process affect the quality of dying. Exploration of the environment of patients in palliative care in hospices, nursing homes, and hospitals by mapping social-spatial experiences to advance the quality of dying will add to the body of knowledge.

**Methods / Methodology** – 57 Employees, volunteers, supervisors, patients, and family were interviewed semi-structured by 7 bachelor thesis students on facilities in Dutch palliative care, after which secondary analysis was performed by one of the authors.

**Results** – Respondents pointed out the importance of spaces and services for spirituality, and indicated that they feel that a sense of control over facilities is important. Connections have been found between spirituality and facilities, and differences between types of roles and types of accommodation. The study illustrates important elements of facilities, such as domestic furniture or decoration, and to the role of spirituality.

**Originality** – Across the field of palliative care in the North of the Netherlands, bachelor thesis students have interviewed staff, volunteers, patients, and family about an interrelated multitude of aspects, including spaces, services, and spirituality.

**Practical or social implications** – Application of findings can potentially contribute to improved alignment of facilities with the needs of patients and their loved ones in palliative care. Differences in opinions of the different groups require further investigation.

**Type of paper** – Research paper.

**KEYWORDS**
Facility management, healthcare, palliative care, space, spirituality, service, quality of dying.

**INTRODUCTION**

The interrelatedness of palliative care with facility management seems to be unexplored territory. According to the WHO (2014) palliative care is an approach that improves the quality of life of patients and their families facing the problems 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. Palliative care integrates the psychological and spiritual aspects of patient care in order to enhance the quality of life of patients. Palliative care is not limited to specialist palliative care services, but includes primary and secondary level care (WHO, 2014). So, the process of dying does not only concern the medical specialists. Facility management is also inextricably interwoven with the delivery of this special care. For instance, the delivery of special services for food, cleaning, and laundry as well as spaces for homeliness, privacy, overnight stays, and spirituality may be crucial supportive factors for patients and their beloved ones (Martens, Witkamp, Mobach, & Roodbol, 2020). In this perspective, facility managers are invited to deliver exactly those spaces and services that fulfill the patient’s needs in their final stage of life. But what exactly are these?

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LITERATURE STUDY

Evidence based design interventions with facility services and spatial structures in palliative care are scarce. This is surprising, because there is an increasing demand from practice. In this context, two developments are relevant. Firstly, a high-quality customer experience (Pine & Gilmore, 1998) is more and more key for customers (Walker, 2020). Secondly, according to the WHO the number of people ageing 65 or above is estimated to grow from 524 million in 2010 to 1.5 billion in 2050 (WHO, 2011). It is only a matter of time that these needs will emerge at ageing populations. More palliative patients and family will expect a high-quality of the experience of dying with dignity. (A complete negation of which is exemplified in the undignified circumstances of many dying patients during the pandemic Corona crisis.) The delivery of the right spaces and services may be crucial. It seems to be a relatively new area in which facility management potentially can add value for the benefit of patients.

Facility management and palliative care do not generate any hit on Google Scholar. Research into palliative care seems to focus on treatments and/or avoidable pain to enable the patients to die with dignity (UN, 2000). Whereas, facility management research focuses on space, infrastructure, people, and organization (European Committee for Standardization, 2006). However, to die with dignity may require better integration.

Stewart et al. (1999) have defined a conceptual framework specifying quality of life and quality of health care indicators, and integrating both. The framework shows that the quality of dying is a broad and complex concept. It is one of the few frameworks that includes patient factors and combines these with the structures, processes, and outcomes of care. For instance, it includes the patient and family situation, the physical environment of care, the satisfaction of patients and family, and the quality of dying.

Stewart et al. (1999) reported that patients and relatives focus increasingly on peace of mind, comfort, and spiritual understanding when arriving at the end of life phase. For many dying persons, attending to spirituality and transcendence is essential. In a recent definition Visser, Garssen, & Vingerhoets (2010) argue that spirituality refers to one’s striving for and experience of a connection with the essence of life of which the experiences of meaning in life and connectedness are central elements. Patients and relatives emphasize personal dignity and the meaningfulness of life rather than physical symptoms or functioning (Puchalski, 2012; Rabitti et al., 2020; Stewart et al., 1999). Physical and cognitive functioning may be important, but in the end-of-life phase other factors matter too. For instance, psychological, social, and spiritual well-being, social functioning, physical comfort, and meaningfulness of life are factors that influence perceived quality of life and dying. Thus, spirituality and related elements are defining elements of facilities for palliative care. Furthermore, in this context a sense of dignity, self-esteem, and control are important elements of psychological well-being. Also, the degree of which patients and families feel they are presented with and can understand various options, are in control, and can make choices autonomously is critical for customer experiences. For instance, a scheduled visit on the calendar of the patient rather than of the health care provider may provide a sense of control.

The structure of care includes the organization of care, support services available, and the physical environment of care. Supportive environments that provide quiet and privacy may greatly improve quality of life. Moreover, the formal support services available (and being accessible) within the health care setting could help to meet the needs of patients and their families. The site of death or the physical location of the patient during the dying process, and the site characteristics (e.g., aesthetics, noise, and opportunities for social interaction) can strongly affect quality of life of dying persons, according to Stewart et al. (1999).

This current paper is an exploration into the services and spaces that facility managers can provide for patients and their relatives in palliative care, and by doing so, to meet their needs, provide dignity, and alleviate their grief.

METHODS

In recent years, bachelor thesis students collected interview data on aspects of palliative care. In this current study, this information was compiled and re-examined. All complete transcripts were collected.
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by one of the authors and were subject to a secondary analysis (Heaton, 2004). The interviews were coded and analysed based on non-medical factors of Stewart’s conceptual model of quality of life of dying patients and their family (Stewart et al., 1999). Facility management tends to focus on practical matters; however, a crucial element of palliative care is spiritual well-being. Therefore, it was included in this research.

The sample consists of 57 interviews conducted by 7 different researchers. The interviewees were selected by the interviewers based on availability. The interviewees were associated with various types of organizations, i.e. hospices, nursing homes, hospitals, and a patient meeting centre. The interviewees were active in various roles, i.e. as volunteers, supervisors, employees, experts, patients, or family. An overview of the sample is shown in Table 1 below.

<table>
<thead>
<tr>
<th>Type of organization</th>
<th>Qty</th>
<th>Role</th>
<th>Qty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice</td>
<td>32</td>
<td>Volunteer</td>
<td>27</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>9</td>
<td>Supervisor</td>
<td>19</td>
</tr>
<tr>
<td>Hospital</td>
<td>5</td>
<td>Employee</td>
<td>5</td>
</tr>
<tr>
<td>Patient Meeting Center</td>
<td>10</td>
<td>Patient &amp; Family</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>Expert</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>57</td>
<td>Total</td>
<td>57</td>
</tr>
</tbody>
</table>

Semi-structured interviews were conducted with topic lists and open questions (Berg, 2009). As mentioned, the interviews were conducted as part of a set of different smaller studies into palliative care, using different topic lists. In all cases, the original interview topic was palliative care, with an emphasis on services and spaces. The interviews lasted an average of 45 minutes (min. 20 minutes, max. 82 minutes, sd = 19 minutes) and were verbatim transcribed by the interviewers. A total of 57 interviews was used for this secondary analysis.

After careful reading, the interviews were coded by one of the authors. Coding was carried out on the basis of a code list consisting of the inductive label ‘sense of control’, and the deductive labels ‘facilities’, ‘interior’, and ‘spirituality’, in line with Miles and Huberman (1994). The labels correspond with Stewarts’ factors satisfaction with healthcare, support services, site characteristics, and spirituality.

The analysis had to be exploratory, because antecedents and outcomes in this research field need further scrutiny. Firstly, the sense of control over the environment, and spirituality were analysed on the basis of quotations of interviewees. Additionally, the sample consisted of different types of organizations and roles of interviewees. Groups have been compiled based on the availability of the number of interviews per group: 32 interviews with respondents in hospices were compared with 14 interviews in nursing homes and hospitals, and 27 interviews with volunteers were compared with 19 interviews with supervisors. These two specific selections were made based on numbers and indications in the data that differences would be found there. Subsequently, the tactic to find contrasts and patterns, and the tactic to count have been used to generate meaning to the qualitative data, as suggested by Miles and Huberman (1994). Quotations from the different groups were examined for patterns with specific tools that are available in the Computer Aided Qualitative Data Analysis System (CAQDAS)\(^1\). The most obvious differences between the different groups were explored with two matrix analyses.

RESULTS

Quotations about facilities and interior were frequently found in the dataset. In addition, inductive quotations were discovered about sense of control. Although none of the interviews had spirituality as a research topic, related quotations were nevertheless identified.

**Sense of control over the facilities**

Most of the quotations by respondents are about sense of control (403) and the environment or facilities (360), and a combination of both in 64 of those cases. Examples of control over facilities are the operation of room lighting, awning, privacy, or even cooking by the family. Respondents mentioned:

\(^1\) The CAQDAS used was Atlas.ti, version 8.4.24.0
“... we can fix that ourselves ...” (supervisor in a nursing home), patients have “… their own sheets and pillow cases …” (volunteer in a hospice), or “The U-Haul drives up. And cabinets, furniture, chairs, everything is unloaded ...” (supervisor in a hospice).

The top 10 comments about building and facility services are as follows:
1. welcoming (56),
2. homeliness (54),
3. view from the window (52),
4. furniture (50),
5. scent (46),
6. decoration (40),
7. colour (40),
8. bathroom (34),
9. lighting (32) and,
10. garden (31).

These quotations cover the interior (81), the environment (325), and the opinion about interior and environment (81), such as:

“that [other home] was much more impersonal” (patient transferred to another nursing home) or “I’ve never heard anyone about the colours” (supervisor in a nursing home).

Other aspects that contribute to feelings or statements about the facilities are, for example, windows that can be opened, music, or the atmosphere of the room in general. All in all, a volunteer mentioned that:

“... the interior of the room is considered important...” (volunteer in a hospice).

**Spirituality**

Spirituality emerged clearly from the data. This means that although spirituality was not part of the research question of the secondary data, 78 comments about spiritual well-being were spontaneously made by more than half of the respondents (30 out of 57). Respondents reported issues like the availability of a spiritual care provider, the needs of patients and family to talk about the questions of life and the acceptance of fate, the presence of a Bible or wake box, rituals, and taboos. Examples of typical quotes can be found in Table 2.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Quote</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counselling and care</td>
<td>“At the intake we always ask whether they are religious”</td>
<td>Supervisor nursing home</td>
</tr>
<tr>
<td>Wish to talk</td>
<td>“My family and friends have had enough of talking” and “they have questions about their life”</td>
<td>Supervisor hospice</td>
</tr>
<tr>
<td>Acceptance of fate</td>
<td>“What should I do at my house?” Interviewer: “That is something that you have ended.” Interviewee: “Yes”</td>
<td>Patient hospice</td>
</tr>
<tr>
<td>Meaningfulness of life</td>
<td>“We actually still celebrate life here”</td>
<td>Supervisor hospice</td>
</tr>
<tr>
<td>Rituals</td>
<td>“… read from the Bible.”</td>
<td>Supervisor nursing home</td>
</tr>
<tr>
<td>Taboos</td>
<td>“So beautiful, I didn’t expect that”</td>
<td>Patient hospice</td>
</tr>
</tbody>
</table>

**Spirituality and facilities**

Spirituality was mentioned in combination with facilities and spaces. A supervisor in a hospice mentioned: ‘We have a so-called ‘wake box’, ‘And it contains, for example, a bible.’ A volunteer in a patient meeting centre reported on the shape of the table: ‘The oval tables bring people closer together. There is more distance at the round tables,’ and another volunteer in a hospice said that: ‘Some people want to be
read from the Bible.’ ‘We have a large white candle and it is always lit when a guest has died’, or ‘... talking to a pastor or a vicar and all that is very welcome ... there is just room for here ... in the guest’s room usually.’ (volunteer in hospice).

Matrix analysis
Matrix analyses were carried out on differences between groups in the sample. Hospices were compared with combined results at nursing homes and hospitals (Table 3), and supervisors were compared with volunteers (Table 4). For each group the total number of quotations, the number of quotations per respondent, and the relative number of quotations are listed consecutively.

### Table 3
Number of quotations per respondent’s role in hospices vs. nursing homes and hospitals.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Hospices (n=31)</th>
<th>Quot. Nurs.Homes &amp; Hospitals (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>Facilities</td>
<td>166</td>
<td>5.4</td>
</tr>
<tr>
<td>Interior</td>
<td>105</td>
<td>3.4</td>
</tr>
<tr>
<td>Sense of Control</td>
<td>181</td>
<td>5.8</td>
</tr>
<tr>
<td>Spirituality</td>
<td>87</td>
<td>2.6</td>
</tr>
</tbody>
</table>

Note 1: Quotations reported by all roles.
Note 2: Row 2 and 5: absolute number of quotations derived from CAQDAS. Row 3 and 6: average number of quotations per respondent. Row 4 and 7: number of quotations relative to the group compared.

As can be seen in Table 3, respondents in hospices report 3.2 more on facilities, 2.2 times as much on sense of control and 2.6 times more on spirituality. Respondents in nursing homes and hospitals report 2.6 times more on interior.

The following table (Table 4) shows that supervisors report 2.1 times more on facilities and 4.9 times more on sense of control. Volunteers report 4.2 times more on interior and 2.2 more on spirituality.

### Table 4
Number of quotations of supervisors vs. volunteers

<table>
<thead>
<tr>
<th>Factors</th>
<th>Supervisors (n=19)</th>
<th>Volunteers (n=27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>Facilities</td>
<td>163</td>
<td>8.6</td>
</tr>
<tr>
<td>Interior</td>
<td>11</td>
<td>0.6</td>
</tr>
<tr>
<td>Sense of Control</td>
<td>221</td>
<td>11.6</td>
</tr>
<tr>
<td>Spirituality</td>
<td>28</td>
<td>14.7</td>
</tr>
</tbody>
</table>

Note 1: Quotations reported in all types of organizations
Note 2: Row 2 and 5: absolute number of quotations derived from CAQDAS. Row 3 and 6: average number of quotations per respondent. Row 4 and 7: number of quotations relative to the group compared.

In summary, respondents in hospices report facilities, sense of control, and spirituality relatively more. In nursing homes and hospitals respondents reported the interior more often. In addition, supervisors are relatively more aware of facilities and sense of control, whereas volunteers are relatively more concerned with interior and spirituality. Lastly, to indicate where sense of control over the environment and spirituality coincide, a comments about a religious person, who:

“... had a very large wooden crucifix. Very bluntly said, it was a huge obstacle, but she was so attached to it. So, that’s why it could stay.” (employee in a hospice)
DISCUSSION
Facilities for palliative care require a sense of homeliness and welcome. This exploratory research indicates that reported facilities should enable autonomy and self-control, like room lighting and awnings. The layout should provide privacy. The facility should ideally offer views from room windows, homely furniture and decoration, a pleasant colour scheme and scent, and a kitchen and bathrooms. Moreover, spiritual well-being plays an important role in palliative care. Interviewees on facility services spontaneously reported experiences related to spirituality and questions of life. Statements about facilities and spaces, co-occur with statements linked to spiritual aspects, for instance, the availability of a Bible or the possibility of a separate space for consultation with a spiritual counsellor. These aspects can be used in palliative facility redesign, and add to the body of knowledge of spirituality in palliative care (Murray, Kendall, Boyd, Worth, & Benton, 2004; Stewart et al., 1999).

Furthermore, we found that the field of palliative care related to facilities is still unchartered territory and has many nuances. Interviews at different locations with different respondents show large differences between groups. First of all, respondents at hospices reported the sense of control over facilities more frequently than respondents at nursing homes and hospitals. In addition, supervisors reported frequently on sense of control, whereas volunteers focused more on interior aspects. These contrasts are an indication that supervisors and people in nursing homes and hospitals have different needs with regards to the sense of control, which require different properties of a facility.

The present dataset is promising. The size and diversity of this research may seem a pitfall, but it provides initial clues and ideas to further explore this terrain and to formulate new research questions. The differences, similarities, and more in-depth insight into the requirements for spiritual well-being may lead to further investigation of this dataset on all factors, e.g. applying Stewart’s model. In any case, research into privacy and single or multi-person rooms as corroboration of Martens et al. (2020) may also be a good follow-up of this current palliative design research.

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The authors declare that they have no competing interests.

REFERENCES


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Deltapremie
The ‘Deltapremie’ or Delta Prize is a new leading research prize in the Netherlands focusing on practice-oriented research by professors. The prize is developed for professors who have managed to repeatedly make a special difference with the social impact of their research over the years. It shows where practice and research can come together in an innovative way. Practice-oriented research has acquired a solid place in Dutch society. Almost 700 professors and more than 3,000 teacher-researchers are currently involved. The starting point of the research is always to find solutions for practice-based problems, also by partnering with practice. In this way, practice-oriented research provides applicable solutions to societal challenges.

An independent selection committee selected the winners. The committee consisted of six experts from Erasmus University Rotterdam, Innofest, Delft University of Technology, Netherlands Study Centre for Technology Trends, and the Association of Netherlands Municipalities. In the report the selection committee tributes Mark Mobach and his research group for the impact that they have on the crossroads of various domains from public transport to mental health. Mobach: “We see the prize as enormous encouragement to continue our research into space and organisation in healthcare, education, offices, and cities together with our partners. We extend our research to areas where there are perhaps fewer financial possibilities, such as research with the arts and frailty.”

Research focus area
With his research group, Prof. Mobach wants to contribute to the best buildings for people and organisations. He does so by devising better space and services in a multidisciplinary setting together with students, lecturer-researchers, Ph.D.-students, and postdocs. Better spaces and services for education, offices, and even cities that stimulate healthy behaviour, better healthcare buildings that reduce stress, but also prisons and stations that better meet the needs of society.