Review Article: End-of-Life Care for Old People: A Review of the Literature
Ingrid Agren Bolmsjo

Am J Hosp Palliat Care 2008; 25; 328 originally published online May 7, 2008;
DOI: 10.1177/1049909108315910

The online version of this article can be found at:
http://ajh.sagepub.com/cgi/content/abstract/25/4/328
A literature search of the PubMed (2007) database focused on end-of-life care, palliative care, terminal care, and individuals at the age of 65 and above. The articles found dealt with problems concerning symptom control, decision making and preferences, the location for dying and death, roles of the family members, and how palliative care should be organized. For example, in a study by Lidstone et al, patients suffering from lung cancer and brain tumors reported severe difficulties and concerns, which implies a need for better symptom control. Another problem area concerns the place of death as terminally ill patients often change their preferences when the need for care increases. The preferences of patients are influenced by the burden of treatment, that is, the length of hospital stay, extent of testing, and invasiveness of interventions. Thus, when planning the care, the staff should be aware of the importance of preferences of patients with regard to the burden of treatment. The preferences of dying patients in hospitals are at risk of being overlooked, although 72% of the patients were aware that they were considered to be dying. The authors underline the importance of evaluating end-of-life decision making and care to facilitate the transition from life-sustaining treatment to palliative care.

The roles of the family members concerning decision making and palliative home care have been
studied by Stajduhar and Davies. The authors found that fulfilling a promise to the patient to care for him or her at home, wanting to maintain a normal family, and previous negative experiences of institutional care influenced the decisions of the family members. Factors associated with home versus institutional death are discussed in an article by Gallo et al. The authors found that being married, female, white, living in a higher income area, type of cancer, and health-resource factors were associated with dying at home rather than in a hospital. Factors that can influence the transition to a hospice are discussed by Schulman-Green et al. Results from interviews with primary caregivers revealed themes related to experiences of the transition to a hospice: acceptance of the impending death by the caregiver, challenges in negotiating health care system along the process of care, and changing patient–family dynamics.

More knowledge of end-of-life care of old people is needed to plan and organize care. In particular, it is important to describe and make an inventory of end-of-life care to date. However, to study the attitudes of the old people and wishes concerning their last period of life is also important. If there are discrepancies between existing end-of-life care and preferences of the old people, it is essential to describe and analyze them. The approach of the present article was to gather information concerning how old people spend their last days, as well as how they would prefer to spend this period. A new, comprehensive literature review may serve as an orientation in this complex area.

Aim

The aim of this article was to describe and make an inventory of various aspects of end-of-life care of the old people. An additional aim was to identify gaps in scientific knowledge.

Method

The literature search in the PubMed database was carried out in steps. In the first step, the search was limited to articles written in English and to individuals who are at the age of 65 and above, after which Medical Subject Headings (MeSH)-terms were identified. Three concepts were of special interest: end-of-life care, palliative care, and terminal care, one of which had to be a key concept (MeSH Major Topic) of the articles. The search was finalized in December 2007 and resulted in the following articles:

- end-of-life care (MeSH Major Topic [(majr]) = 523 articles
- palliative care (majr) = 3216 articles
- terminal care (majr) = 3633 articles

When combining these 3 concepts, the result was: end-of-life care (majr) or palliative care (majr), or terminal care (majr) = 6505 articles.

To identify the most relevant of the above-mentioned articles, a search was made for the term intervention in either the title or abstract. The abbreviation (tiab) was used in the search string: intervention (tiab) or interventions (tiab), which resulted in 51,672 articles. The 2 literature searches were combined with AND, giving a total of 522 articles.

Finally, a limitation in terms of time was decided upon, and articles written before 1990 were excluded. Altogether, the searches yielded 497 references. In the second step, the abstracts were reviewed in relation to the purpose of the study, after which 126 articles were closely scrutinized in terms of their relevance and scientific strength. The inclusion criteria were that the study should refer to interventions in the context of end-of-life care and people at the age of 65 and above. Studies dealing with specific diseases, as well as those mainly focused on life-sustaining treatments, terminal sedation, and euthanasia, were excluded. Thus, in the third step, the 126 studies were evaluated in relation to the inclusion and exclusion criteria, resulting in 29 studies. Finally, scientific strength was evaluated by the Goodman model, which contains criteria related to internal and external validity, reliability, and critical discussion.

Results

Twenty-nine studies were included (Table 1), which were summarized and grouped with respect to the content of interventions and for whom they were intended.

Education and Support for Close Relatives

Hudson et al studied 106 family caregivers of dying patients. The aim was to examine the effect of a psychoeducational intervention for this group. The
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Interventions</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hudson PL et al (2005)</td>
<td>Randomized controlled trial; N = 106 family caregivers</td>
<td>Home visits, phone calls, and questionnaires</td>
<td>Intervention group reported a more positive experience of caregivers. No effects were observed with respect to preparedness for providing care, self-efficacy, competence, and anxiety</td>
</tr>
<tr>
<td>Ringdal GI et al (2001)</td>
<td>Cluster randomized trial; N = 183 family members</td>
<td>Comprehensive palliative care interventions</td>
<td>The grief reactions decreased over time, but there were no differences between the intervention and control group</td>
</tr>
<tr>
<td>Duggleby W et al (2007)</td>
<td>Concurrent triangulation, pretest and posttest design; N = 61 patients</td>
<td>The Living with Hope program</td>
<td>Benefits in fostering hope in family caregivers</td>
</tr>
<tr>
<td>Henriksson A and Andershed B (2007)</td>
<td>Qualitative study; N = 10</td>
<td>Interviews</td>
<td>The ability of the relatives to handle the situation with a terminally ill family member increased</td>
</tr>
<tr>
<td>McMillan SC and Small BJ (2007)</td>
<td>A 3-group comparative design; N = 329 patients</td>
<td>COPE intervention training</td>
<td>Symptom distress decreased significantly in the intervention group</td>
</tr>
<tr>
<td>Baker R et al (2000)</td>
<td>A prospective cohort study, randomized design; N = family members of 767 terminally ill patients</td>
<td>A specialist nurse assisted in symptom control and facilitated communication and decision making</td>
<td>16% reported dissatisfaction with patient comfort and 30% dissatisfaction with communication and decision making</td>
</tr>
<tr>
<td>Walsh K et al (2007)</td>
<td>A GHQ-28 questionnaire</td>
<td>Weekly visits over a 6-wk-period from an experienced advisor</td>
<td>The help of an advisor had little effect</td>
</tr>
<tr>
<td>Schrader SL et al (2002)</td>
<td>Study design without controls. Data were collected from patients, their families, and the hospital records; N = 50 patients</td>
<td>Symptom management, spiritual dialogue, psychosocial counseling, and guidance on advance directives</td>
<td>Improvements were found in pain, nonpain symptom management, psychosocial QoL measures, and perceptions of communication and treatment during hospitalization</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Interventions</td>
<td>Findings</td>
</tr>
<tr>
<td>---------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>London MR et al (2005)21</td>
<td>Prospective observational study; N = 295 patients and families</td>
<td>Comprehensive adaptable life-affirming longitudinal (CALL) care</td>
<td>Improved pain and symptom management was reported. Only 29% were hospitalized, 7% were admitted to critical care/an ICU, 48% used hospice care, and 38% were likely to die at home</td>
</tr>
<tr>
<td>Han PK et al (2005)22</td>
<td>Pilot test, observational study; N = 60 residents</td>
<td>Faculty observers including doctors, a nurse ethicist, and a social worker observed the skills of the trainees in discussing end-of-life issues with seriously ill patients.</td>
<td>The CEX was positively valued by residents.</td>
</tr>
<tr>
<td>Hanson CL et al (2005)23</td>
<td>Chart review; N = 1169 residents</td>
<td>Recruitment and training of palliative care leadership teams</td>
<td>No differences in the use of pain medication. Hospice enrollment, pain assessment, prescriptions for nonpharmacological pain treatment, and discussions with residents about end-of-life care increased in the intervention group</td>
</tr>
<tr>
<td>Stillman et al (2005)24</td>
<td>A questionnaire; N = 6 nursing homes</td>
<td>Staff training, integration of palliative care and support, consultation with an expert nurse</td>
<td>More problems in providing palliative care were identified in the intervention group</td>
</tr>
<tr>
<td>Schwartz CE et al (2002)25</td>
<td>Pilot trial, randomized study; N = 61 patients</td>
<td>Patient and health care provider discussed ACP (advance care planning) with a trained nurse</td>
<td>The intervention group showed higher congruence between patients and providers in the understanding of the end-of-life care preferences of the patients</td>
</tr>
<tr>
<td>Ratner E et al (2001)26</td>
<td>Case studies of patients with a terminal illness; N = 84 patients</td>
<td>Formally structured social work visits to the homes of the patients to discuss end-of-life issues</td>
<td>82% wanted the care to be provided at home, 75% of the deaths occurred at home or in a hospice, 61% used home, residential, or nursing home based services.</td>
</tr>
<tr>
<td>Hilliard E (2003)27</td>
<td>Randomized experimental study; N = 80</td>
<td>Music therapy sessions</td>
<td>Higher QoL in the intervention group</td>
</tr>
<tr>
<td>Freeman L et al; (2006)28</td>
<td>Nonexperimental study; N = 65 patients</td>
<td>Harp music</td>
<td>A vigil could form part of palliative care for dying patients.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Interventions</td>
<td>Findings</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Jerant AF et al (2004)29</td>
<td>Nonblinded, prospective comparison trial; N = 135 residents</td>
<td>Letters containing palliative care recommendations</td>
<td>The TLC model may be beneficial when conducting further interventions</td>
</tr>
<tr>
<td>Jack B et al (2003)30</td>
<td>A nonequivalent control group study; N = patients</td>
<td>Individualized assessment, advice, psychological support, symptom control and evaluation (eg, appropriate analgesia)</td>
<td>The intervention group had a greater improvement in all symptoms, particularly pain and anorexia</td>
</tr>
<tr>
<td>Edmond PM (1998)31</td>
<td>An assessment schedule and questionnaire; N = 352 patients</td>
<td>Use of a modified STAS</td>
<td>E-STAS may be a useful tool for evaluating interventions</td>
</tr>
<tr>
<td>Gutheil IA and Heyman JC (2005)32</td>
<td>A posttest-only control group design; N = 49 older people</td>
<td>Three group sessions with educational and support components</td>
<td>The intervention had an influence on advance communication about wishes pertaining to the end-of-life phase</td>
</tr>
<tr>
<td>Lambing A et al (2006)33</td>
<td>A prospective pilot study; N = 50 patients</td>
<td>A CD-ROM containing topics such as taking charge, obtaining comfort, and reaching closure</td>
<td>90% were satisfied with the CD-ROM.</td>
</tr>
<tr>
<td>Bookbinder M et al (2005)34</td>
<td>Pilot study. A chart audit tool (CAT) was used to review medical records; N = 6 units</td>
<td>Educational program for staff, implementation strategies, and evaluation-feedback tools.</td>
<td>PCAD can serve as an educational tool, be implemented in hospital units, have a positive impact on outcomes, promote proactive symptom assessment and treatment, and units not directly involved in the intervention may also experience change.</td>
</tr>
<tr>
<td>Morita T et al (2005)35</td>
<td>Prospective audit study; N = 211 patients</td>
<td>All patients were followed on a daily basis by a member of the PCT and multidisciplinary rounds were performed once a week</td>
<td>There were significant improvements in many symptoms among the PCT patients</td>
</tr>
<tr>
<td>Casarett DJ et al (2002)36</td>
<td>Chart review; N = 100 patients</td>
<td>Palliative care clinic</td>
<td>Most patients needed at least one of the team services, information about prognosis being the most common</td>
</tr>
<tr>
<td>Brumley RD et al (2003)37</td>
<td>Comparative group design, N = 558 patients</td>
<td>A home-based palliative care program</td>
<td>The intervention group was more satisfied with the services, had fewer emergency department visits, hospital days, skilled nursing care days, and physician visits compared with the control group. The palliative care group had reduced costs compared with the controls.</td>
</tr>
</tbody>
</table>
Table 1. (continued)

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Interventions</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jordhoy MS et al (2000)³⁸</td>
<td>Cluster randomized trial; N = 434 patients</td>
<td>A palliative medicine unit, where the palliative team served as a link to the community. Guidelines were used to facilitate the interaction between services, and education was provided to community professionals</td>
<td>More intervention patients than controls died at home (25% vs 15%)</td>
</tr>
<tr>
<td>Santa-Emma PH et al (2002)³⁹</td>
<td>Data on patient demographics, diagnoses, key symptoms, and outcome were collected by the APCS; N = 3712 patients</td>
<td>Consultations, direct transfers, and admissions, involving the emergency department, home hospice, and referring physician</td>
<td>56.9% were transferred to the APCS, 16.3% were directly admitted, 26.9% were seen in consultation. The most common symptom was dyspnea (53.9%) and 88.7% had 1 to 3 symptoms.</td>
</tr>
<tr>
<td>Brumley R et al (2007)⁴⁰</td>
<td>A randomized controlled trial; N = 298</td>
<td>Standard versus in-home palliative care plus standard care</td>
<td>The intervention group reported an improvement in satisfaction with care, and its members were more likely to die at home.</td>
</tr>
<tr>
<td>Rabow MW et al (2004)⁴¹</td>
<td>Controlled study, cluster randomization; N = 90 patients</td>
<td>The palliative care program integrated primary care physician, consultations, case management, volunteer and group support, chaplaincy consultation, and artistic expression</td>
<td>The comprehensive care team resulted in less dyspnea and anxiety in addition to greater spiritual wellbeing but failed to improve pain or depression.</td>
</tr>
</tbody>
</table>

Abbreviations: APCS, acute palliative care service; CEX, palliative care clinical evaluation exercise; COPE, creativity, optimism, planning, expert information; E-STAS, expanded STAS; GHQ-28, general health questionnaire; ICU, intensive care unit; PCAD, palliative care for advanced disease; PCT, palliative care team; QoL, quality of life; STAS, support team assessment schedule.
intervention was provided by nurses and consisted of 2 home visits, telephone calls, and questionnaires. The result showed that the participants perceived the caregivers in a more positive light. However, no effects concerning preparedness to provide care, self-efficacy, competence, or anxiety were observed.

Ringdal et al14 investigated family members to examine grief reactions when a loved one had died of cancer. The intervention consisted of comprehensive palliative care. The findings revealed no differences between the intervention group and controls.

In 2 separate studies, the authors examined a living with hope program15 and a support group program for relatives who had a terminally ill family member.16 The results of both studies showed that the programs may be useful tools in helping relatives cope with their situation when caring for a terminally ill loved one.

The COPE (creativity, optimism, planning, expert information) intervention was tested on family caregivers of the hospice homecare patients.17 The main finding was that distress decreased among caregivers who had been trained to manage the symptoms of the patients.

Baker et al18 studied the factors associated with family satisfaction, such as symptom control, communication, and decision making. The authors found that 16% of respondents were dissatisfied with patient comfort and 30% with communication and decision making.

Walsh et al19 evaluated the effectiveness of increased support for distressed informal carers. A trained advisor visited the informants once a week for a period of 6 weeks. No significant differences were found.

One article had a double perspective20; the interventions were directed toward both patients and families and included symptom management, spiritual dialogue, psychosocial counseling, and guidance on advance directives. The main findings showed improvements in symptom management, psychosocial quality of life (QoL) measures, and perceptions of communication and treatment.

London et al21 evaluated whether CALL (comprehensive, adaptable, life affirming, longitudinal) care had any effect on seriously ill patients and their families. The authors found that apart from improved pain and symptom management, 29% were hospitalized, 7% were admitted to critical care, 48% received hospice care, and 38% were likely to die at home.

Education and Support for Staff
An educational trial was conducted in a study by Han et al22 that aimed at testing CEX (palliative care clinical evaluation exercise): an intervention to teach trainees the communication skills, including end-of-life issues. The results indicated that CEX appear to be a useful educational tool.

The aim of the study by Hanson et al23 was to test whether a quality improvement intervention in nursing homes increases hospice, pain management, and advance care planning. The intervention included the training of palliative care leadership teams, facilitating meetings for team members, and educational sessions for staff. The findings showed that although the use of pain medication remained unchanged, hospice enrollment, pain assessment, prescriptions for nonpharmacological pain treatment, and discussions with residents about end-of-life care increased in the intervention group.

Stillman et al24 carried out a study in which the aim was to determine whether a comprehensive palliative care program in nursing homes would affect staff knowledge and attitudes. The intervention consisted of staff training, integration of palliative care principles, support, and consultation with an expert nurse. The authors concluded that the intervention group was more open to problems encountered in the provision of palliative care compared with controls.

In the study conducted by Schwartz et al,25 the intervention was aimed at both health care personnel and patients. The benefit of discussing advance care planning with a trained nurse was evaluated. The result showed increased agreement between health care professionals and patients, concerning the latters’ end-of-life care preferences.

Education and Support for Patients
Ratner et al26 examined whether the formally structured visit of the social worker to homes of the patients in the end-of-life phase made it easier to discuss issues related to dying and death. The authors found that 82% wished for the care to be provided at home, 75% of deaths occurred at home or in a hospice and that 61% used home, residential, or nursing home services.

Hilliard27 and Freeman et al28 examined the effect of music therapy in terminally ill patients. In both the studies, the music therapy sessions improved the QoL of the patients.
Jerant et al.\textsuperscript{29} carried out a study involving very old people. The study was based on the T (time and team oriented) L (longitudinal) C (collaborative and comprehensive) model. One main finding was that the patients placed a higher value on QoL than on prolonging life.

Jack et al.\textsuperscript{30} investigated whether a hospital-based palliative care team could improve the symptoms of the cancer patients by psychological support and appropriate analgesia. The results showed that pain and anorexia decreased for patients in the intervention group.

Edmond et al.\textsuperscript{31} investigated the use of a modified STAS (support team assessment schedule). A total of 352 patients participated in the study. Ninety-three percent of patients reported psychological distress on referral, 73% anorexia, 59% pain, and 59% mouth discomfort.

Gutheil and Heyman\textsuperscript{32} carried out a study aimed at evaluating an intervention to help older people communicate their wishes with regard to end-of-life care. Three sessions containing education and support had a positive effect on advance communication about these wishes.

Lambing et al.\textsuperscript{33} evaluated a CD-ROM containing topics such as taking charge, finding comfort, and reaching closure. Ninety percent of the patients were of the opinion that a CD-ROM could be a useful and complementary tool.

**Articles Dealing With Care Planning**

Bookbinder et al.\textsuperscript{34} conducted a study on palliative care for advanced disease (PCAD). The intervention consisted of an educational program, implementation strategies, and evaluation of the feedback tools. The main findings indicated that PCAD can serve as a useful educational tool.

Morita et al.\textsuperscript{35} compared the patients referred to a palliative care team (PCT) with a multidisciplinary approach and to a palliative care unit (PCU). All patients were followed on a daily basis by a member of the PCT, and multidisciplinary rounds were performed once in a week. The authors found that there were significant improvements in many symptoms among the PCT patients.

Interventions including a palliative care clinic (PCC) were assessed in a study by Casarett et al.\textsuperscript{36} The clinic provided consultations about symptom management, hospice eligibility, information about services, as well as advance care planning. The findings showed that most of the patients required at least 1 of the team services, the most common being a need for information about the prognosis.

Brumley et al.\textsuperscript{37} investigated the effect of a palliative care program on end-of-life care. The results showed that patients who were included in the intervention group were more satisfied with services and had fewer emergency department visits, skilled nursing facility days, and physician visits, which led to a 45% reduction in health care costs.

A palliative care unit was examined in a study by Jordhoy et al.\textsuperscript{38} In the intervention group, 25% died at home compared with 15% of the controls.

Santa-Emma et al.\textsuperscript{39} evaluated acute palliative care service (APCS). The main findings were that 56% of patients were transferred to the APCS and that the most common symptom was dyspnea (53%).

Brumley et al.\textsuperscript{40} investigated whether an in-home palliative care intervention had an impact on patient satisfaction, reduced medical care costs, and/or increased number of patients dying at home. In summary, the results showed that patients in the intervention group reported greater satisfaction with care and were more likely to die at home compared with the controls.

Rabow et al.\textsuperscript{41} evaluated an outpatient palliative medicine consultation. The patients were provided with an interdisciplinary palliative care program, including physician consultation, case management, support, chaplaincy consultation, and artistic expression. The comprehensive care team (CCT) brought about a reduction in dyspnea and anxiety, as well as greater spiritual wellbeing, although no improvement in terms of pain or depression was reported.

**Discussion**

The present literature review resulted in 29 articles. However, most studies came from the USA, which implies the need for caution when interpreting the results. The cultural context differs from that of Europe, and even European countries differ from each other in terms of culture. This finding underlines the need for studies carried out in other cultural and geographical settings. When discussing ease and relief in the context of palliative care, the focus should not only be on physical pain but also on the additional dimensions of suffering, which differ in line with culture.\textsuperscript{42} Thus, it is important to investigate the meaning of suffering in different cultures.

Although much has been done to develop palliative care practice, problems still remain. One main difficulty...
relates to scope: who should have access to palliative care? New research published by The International Observatory on End of Life Care (IOELC) at Lancaster University has found that in 78 countries (234 countries were included in their review), no palliative care activity was available, and around half of the included countries had established one or more palliative care services. These findings point to the need for further indepth research. From an ethical perspective, this is also a question of social justice.

In the present article, a crucial question is the access of old people to palliative care. Empirical studies are needed to investigate the extent to which old people have access to palliative care, and normative problems should also be addressed. For example, is there any reason why old people should not have access to palliative care? Few studies focused on the very old people, that is, individuals at the age of 80 and above. For most individuals, the life span between 65 and 80 to 90 will include different phases. For example, at 65 to 70 years, an individual can still be productive and alert, whereas the years from 70 to 90 may be filled with experiences of becoming more and more dependent on the health care system, as well as on close family members and on others who are significant. However, with regard to social justice, palliative care for everybody who suffers from a terminal disease is a goal worth striving for. Therefore, more studies are required on the need and preferences of very old people. Jerant et al described a palliative care model for old people, the TLC (Time and Team oriented, Longitudinal, and Collaborative and Comprehensive) model. The model comprises 3 components: (a) palliative care must be timely to avoid unnecessary suffering, as well as team-oriented where trained nurses play a central role, (b) it should be longitudinal with a balance of palliative and curative measures, and (c) the care should be collaborative and comprehensive, with attention to existential issues.

Family members and other close ones play a central role in end-of-life care. In a doctoral dissertation by Andersson, the author points out that the responsibility for the patient and the need for professional support were the main issues for the family members of the old people. Problems related to family relationships have only been studied to a limited extent. However, the notion of the family as a problematic unit is highlighted in a study by Coleen Fisher. The author states that we should be aware of the problem of abusive family relationships. This issue needs to be identified if the goal of holistic care is to be obtained.

Another problem concerning informal caregivers of terminally ill patients was pointed out by Harding and Higginson who showed that carers often see their role as a duty and lack self-identity, which means that they are highly ambivalent. Kissane et al described the family grief therapy model, which could serve as a tool in helping families to cope with their grief and improve their functioning.

Some of the articles presented in the Result section deal with questions concerning how palliative care could be better organized. The palliative care consultation services model is intended to improve the quality of end-of-life care. However, Han and Arnold discussed patient abandonment as an unintended outcome of a palliative care service and suggested that the ethical problems raised by the responsibility of the staff should be taken seriously. Their article highlights questions related to a good death for old people. Hanson et al have identified 3 factors that hinder a good death in a nursing home: lack of training, lack of focus on rehabilitation, and lack of resources. Moreover, 3 themes appeared important in the definition of a good death: individualized care, good relationships with the care team, and comprehensive advance care planning. The findings of the study by Hanson et al confirm the results of the present study, that is, many of the intervention studies aim to improve end-of-life care of old people by focusing on team work and care planning.

Another problem is that much research in this area is based on empirical data with a study design, which does not allow for any generalizations of the findings. This in turn is associated with the palliative care context, which is problematic because of the extremely vulnerable patients. Most of the palliative care researches to date have focused on the identification of patient and family needs, the gaps in the health care system, and the need for staff education. However, Morrison points out that the results of most studies are limited because of the methodological weaknesses and underlines the importance of comprehensive research, including robust, that is reliable and valid, studies to evaluate the effect of generalizable palliative care structures.

Conclusions

End-of-life care is a much debated topic. One reason may be that, by its nature, it does not lend itself to
large randomized controlled studies; thus, questions remain to be answered. In this article, gaps concerning scientific knowledge have been identified. More knowledge is needed in the following areas: the end-of-life care in geographical and cultural settings other than the USA, old people’s needs and preferences concerning end-of-life care, and the effect of adjusted and generalizable palliative care models.

Acknowledgments

I want to express my gratitude to Rigmor Fransson, librarian, the Vardal Institute, for valuable help. Lund and Gothenburg University, Sweden, for financial support.

References


