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End-of-Life Care for Old People: A Review of the Literature

Ingrid Agren Bolmsjo, PhD, BTh

The aim of this study was to make an inventory of various aspects of end-of-life care of the old people. An additional aim was to illuminate gaps in existing knowledge. A systematic literature review focusing on intervention studies was carried out. Three concepts were of special interest: end-of-life care, palliative care, and terminal care. The result encompassed 29 studies, and the articles were grouped together under 4 headings: education and support for close relatives, education and support for staff, education and support

for patients, and articles dealing with care planning. The result highlights the need for further research regarding end-of-life care in geographical and cultural settings that differ from those in the USA, needs of old people (ie, 80+), preferences concerning end-of-life care, and the effect of adjusted and generalizable palliative care models.

Keywords: end-of-life care; palliative care; old people; review

Although death and dying are a natural part of life, the increase in the number of very old people implies challenges for those responsible for their care. For example, most of the very old people have multiple, as well as chronic, diseases, which necessitate frequent hospitalization.¹

Little research has been conducted on very old people and the last period of their life.² However, Nahm and Resnick³ focused on elderly individuals and the importance of giving them opportunities to discuss their end-of-life preferences. In terms of treatment preferences, the results of their study indicate that many older people do not want invasive interventions but prefer comforting measures. Moreover, their preferences may change over time; therefore, it is essential to reevaluate them regularly. The use of intensive care at the end-of-life increases with age and with the number of coexisting chronic illnesses.⁴ As mentioned previously, old people have specific care needs. Therefore, it is essential to provide them with adjusted interventions.

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,⁵ 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.⁶ 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.⁷ 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.⁸ 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

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studied by Stajduhar and Davies.⁹ 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.¹⁰ 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.¹¹ 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.¹² 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,¹² 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 al¹³ studied 106 family caregivers of dying patients. The aim was to examine the effect of a psychoeducational intervention for this group. The

Table 1. Summary of Findings

Study	Design	Interventions	Findings
Hudson PL et al (2005) ¹³	Randomized controlled trial; N = 106 family caregivers	Home visits, phone calls, and questionnaires	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
Ringdal GI et al (2001) ¹⁴	Cluster randomized trial; N = 183 family members	Comprehensive palliative care interventions	The grief reactions decreased over time, but there were no differences between the intervention and control group
Duggleby W et al (2007) ¹⁵	Concurrent triangulation, pretest and posttest design; N = 61 patients	The Living with Hope program	Benefits in fostering hope in family caregivers
Henriksson A and Andershed B (2007) ¹⁶	Qualitative study; N = 10	Interviews	The ability of the relatives to handle the situation with a terminally ill family member increased
McMillan SC and Small BJ (2007) ¹⁷	A 3-group comparative design; N = 329 patients	COPE intervention training	Symptom distress decreased significantly in the intervention group
Baker R et al (2000) ¹⁸	A prospective cohort study, randomized design; N = family members of 767 terminally ill patients	A specialist nurse assisted in symptom control and facilitated communication and decision making	16% reported dissatisfaction with patient comfort and 30% dissatisfaction with communication and decision making
Walsh K et al (2007) ¹⁹	A GHQ-28 questionnaire	Weekly visits over a 6-wk-period from an experienced advisor	The help of an advisor had little effect
Schrader SL et al (2002) ²⁰	Study design without controls. Data were collected from patients, their families, and the hospital records; N = 50 patients	Symptom management, spiritual dialogue, psychosocial counseling, and guidance on advance directives	Improvements were found in pain, nonpain symptom management, psychosocial QoL measures, and perceptions of communication and treatment during hospitalization

(continued)

Table 1. (continued)

Study	Design	Interventions	Findings
London MR et al (2005) ²¹	Prospective observational study; N = 295 patients and families	Comprehensive adaptable life-affirming longitudinal (CALL) care	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 The CEX was positively valued by residents.
Han PK et al (2005) ²²	Pilot test, observational study; N = 60 residents	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.	
Hanson CL et al (2005) ²³	Chart review; N = 1169 residents	Recruitment and training of palliative care leadership teams	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
Stillman et al (2005) ²⁴	A questionnaire; N = 6 nursing homes	Staff training, integration of palliative care and support, consultation with an expert nurse	More problems in providing palliative care were identified in the intervention group
Schwartz CE et al (2002) ²⁵	Pilot trial, randomized study; N = 61 patients	Patient and health care provider discussed ACP (advance care planning) with a trained nurse	The intervention group showed higher congruence between patients and providers in the understanding of the end-of-life care preferences of the patients
Ratner E et al (2001) ²⁶	Case studies of patients with a terminal illness; N = 84 patients	Formally structured social work visits to the homes of the patients to discuss end-of-life issues	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.
Hilliard E (2003) ²⁷	Randomized experimental study; N = 80	Music therapy sessions	Higher QoL in the intervention group
Freeman L et al; (2006) ²⁸	Nonexperimental study; N = 65 patients	Harp music	A vigil could form part of palliative care for dying patients.

(continued)

Table 1. (continued)

Study	Design	Interventions	Findings
Jerant AF et al (2004) ²⁹	Nonblinded, prospective comparison trial; N = 135 residents	Letters containing palliative care recommendations	The TLC model may be beneficial when conducting further interventions
Jack B et al (2003) ³⁰	A nonequivalent control group study; N = patients	Individualized assessment, advice, psychological support, symptom control and evaluation (eg, appropriate analgesia)	The intervention group had a greater improvement in all symptoms, particularly pain and anorexia
Edmond PM (1998) ³¹	An assessment schedule and questionnaire; N = 352 patients	Use of a modified STAS	E-STAS may be a useful tool for evaluating interventions
Gutheil IA and Heyman JC (2005) ³²	A posttest-only control group design; N = 49 older people	Three group sessions with educational and support components	The intervention had an influence on advance communication about wishes pertaining to the end-of-life phase
Lambing A et al (2006) ³³	A prospective pilot study; N = 50 patients	A CD-ROM containing topics such as taking charge, obtaining comfort, and reaching closure	90% were satisfied with the CD-ROM.
Bookbinder M et al (2005) ³⁴	Pilot study. A chart audit tool (CAT) was used to review medical records; N = 6 units	Educational program for staff, implementation strategies, and evaluation-feedback tools.	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.
Morita T et al (2005) ³⁵	Prospective audit study; N = 211 patients	All patients were followed on a daily basis by a member of the PCT and multidisciplinary rounds were performed once a week	There were significant improvements in many symptoms among the PCT patients
Casarett DJ et al (2002) ³⁶	Chart review; N = 100 patients	Palliative care clinic	Most patients needed at least one of the team services, information about prognosis being the most common
Brumley RD et al (2003) ³⁷	Comparative group design, N = 558 patients	A home-based palliative care program	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.

(continued)

Table 1. (continued)

Study	Design	Interventions	Findings
Jordhoy MS et al (2000) ³⁸	Cluster randomized trial; N = 434 patients	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	More intervention patients than controls died at home (25% vs 15%)
Santa-Emma PH et al (2002) ³⁹	Data on patient demographics, diagnoses, key symptoms, and outcome were collected by the APCS; N = 3712 patients	Consultations, direct transfers, and admissions, involving the emergency department, home hospice, and referring physician	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.
Brumley R et al (2007) ⁴⁰	A randomized controlled trial; N = 298	Standard versus in-home palliative care plus standard care	The intervention group reported an improvement in satisfaction with care, and its members were more likely to die at home.
Rabow MW et al (2004) ⁴¹	Controlled study, cluster randomization; N = 90 patients	The palliative care program integrated primary care physician, consultations, case management, volunteer and group support, chaplaincy consultation, and artistic expression	The comprehensive care team resulted in less dyspnea and anxiety in addition to greater spiritual wellbeing but failed to improve pain or depression.

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 latter's 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 al²⁹ 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 al³⁰ 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 al³¹ 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 Heyman³² 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 al³³ 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 al³⁴ 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 al³⁵ 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.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 al³⁷ 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.³⁸ In the intervention group, 25% died at home compared with 15% of the controls.

Santa-Emma et al³⁹ 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 al⁴⁰ 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 al⁴¹ 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.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 University⁴³ 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 in-depth 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.⁴⁴ Therefore, more studies are required on the need and preferences of very old people. Jerant et al²⁹ 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,¹ 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.⁴⁵ 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 Higginson⁴⁶ who showed that carers often see their role as a duty and lack self-identity, which means that they are highly ambivalent. Kissane et al⁴⁷ 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 Arnold⁴⁸ 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 al⁴⁹ 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 al⁴⁹ 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, Morrison⁵⁰ 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.

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References

- Andersson M. Äldre personers sista tid i livet. (Old people's last phase in life) [Doctoral dissertation]. Sweden: Lund Univ.; 2007.
- Rahm Hallberg I. Death and dying from old people's point of view. A literature review. *Aging Clin Exp Res*. 2004;16:87-103.
- Nahm E-S, Resnick B. End-of-life treatment preferences among older adults. *Nurs Ethics*. 2001;8:6.
- Seferian EG, Afessa B. Adult intensive care unit use at the end of life: a population-based study. *Mayo Clin Proc*. 2006;81:896-901.
- Lidstone V, Butters E, Sinnott C, Beynon T, Richards M. Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. *Palliat Med*. 2003;17:588-595.
- McCall K, Rice AM. What influences decisions around the place of care for terminally ill cancer patients? *Int J Palliat Nurs*. 2005;11:10.
- Fried TR, Bradley EH, Towle VR, Allore H. Understanding the treatment preferences of seriously ill patients. *N Eng J Med*. 2002;346:14.
- Fins JJ, Miller FG, Acres CA, Bacchetta MD, Huzzard LL, Rapkin BD. End-of-life decision-making in the hospital: current practice and future prospects. *J Pain Symptom Manage*. 1999;17:1.
- Stajduhar KI, Davies B. Variations in and factors influencing family members' decisions for palliative home care. *Palliat Med*. 2005;19:21-32.
- Gallo WT, Baker MJ, Bradley EH. Factors associated with home versus institutional death among cancer patients in Connecticut. *J Am Geriatr Soc*. 2001;49:771-777.
- Schulman-Green D, McCorkle R, Curry L, Cherlin E, Hurzeler-Johnson R, Bradley E. At the crossroads: making the transition to hospice. *Palliat Supp Care*. 2004;2:351-360.
- Goodman C. *Literature Searching and Evidence Interpretation for Assessing Health Care Practices*. Stockholm, Sweden: SBU; 1993.
- Hudson PL, Aranda S, Hayman-White K. A psycho-educational intervention for family caregivers of patients receiving palliative care: a randomized controlled trial. *J Pain Symptom Manage*. 2005;30:329-341.
- Ringdal GI, Jordhoy MS, Ringdal K, Kaasa S. Factors affecting grief reactions in close family members of individuals who have died of cancer. *J Pain Symptom Manage*. 2001;22:1016-1026.
- Duggleby W, Wright K, Williams A, Degner L, Cammer A, Holtslander L. Developing a living with hope program for caregivers of family members with advanced cancer. *J Palliat Care*. 2007;23:24-31.
- Henriksson A, Andershed B. A support group programme for relatives during the late palliative phase. *Int J Palliat Nurs*. 2007;13:175-183.
- McMillan SC, Small BJ. Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. *Onc Nurs Forum*. 2007;34:2.
- Baker R, Wu AW, Teno JM, et al. Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J Am Geriatr Soc*. 2000;48(5 Suppl):S61-S69.
- Walsh K, Jones L, Tookman A, et al. Reducing emotional distress in people caring for patients receiving specialist palliative care. Randomised trial. *Br J Psych*. 2007;190:142-147.
- Schrader SL, Horner A, Eidsness L, Young S, Wright C, Robinson M. A team approach in palliative care: enhancing outcomes. *SDJ Med*. 2002;55:269-278.
- London MR, McSkimming S, Drew N, Quinn C, Carney B. Evaluation of a Comprehensive, Adaptable, Life-Affirming, Longitudinal (CALL) palliative care project. *J Palliat Med*. 2005;8:1214-1225.
- Han PK, Keranen LB, Lescisin DA, Arnold RM. The palliative care clinical evaluation exercise (CEX): an experience-based intervention for teaching end-of-life communication skills. *Acad Med*. 2005;80:669-676.
- Hanson LC, Reynolds KS, Henderson M, Pickard CG. A quality improvement intervention to increase palliative care in nursing homes. *J Palliat Med*. 2005;8:576-584.
- Stillman D, Strumpf N, Capezuti E, Tuch H. Staff perceptions concerning barriers and facilitators to end-of-life care in the nursing home. *Geriatr Nurs*. 2005;26:259-264.
- Schwartz CE, Wheeler HB, Hammes B, et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: results of a pilot trial. *Arch Intern Med*. 2002;162:1611-1618.
- Ratner E, Norlander L, McSteen K. Death at home following a targeted advance-care planning process at home: the kitchen table discussion. *J Am Geriatr Soc*. 2001;49:778-781.

27. Hilliard E. The effect of music therapy on the quality and length of life of people diagnosed with terminal cancer. *J Music Therapy*. 2003;40:113-137.
28. Freeman L, Caserta M, Lund D, Rossa S, Dowdy A, Partenheimer A. Music thanatology: prescriptive harp music as palliative care for the dying patient. *Am J Hosp Palliat Care*. 2006;23:100-104.
29. Jerant AF, Azari RS, Nesbitt TS, Meyers FJ. The TLC model of palliative care in the elderly: preliminary application in the assisted living setting. *Ann Fam Med*. 2004;2:54-60.
30. Jack B, Hillier V, Williams A, Oldham J. Hospital based palliative care teams improve the symptoms of cancer patients. *Palliat Med*. 2003;17:498-502.
31. Edmond PM, Stuttaford JM, Penny J, Lynch AM, Chamberlain J. Do hospital palliative care teams improve symptom control? Use of a modified STAS as an evaluation tool. *Palliat Med*. 1998;12:345-351.
32. Gutheil IA, Heyman JC. Communication between older people and their health care agents: results of an intervention. *Health Soc Work*. 2005;30:107-116.
33. Lambing A, Markey CA, Neslund-Dudas CM, Bricker LJ. Completing a life: comfort level and ease of use of a CD-ROM among seriously ill patients. *Oncol Nurs Forum*. 2006;33:999-1006.
34. Bookbinder M, Blank AE, Arney E, et al. Improving end-of-life care: development and pilot-test of a clinical pathway. *J Pain Symptom Manage*. 2005;29:529-543.
35. Morita T, Fujimoto K, Tei Y. Palliative care team: the first year audit in Japan. *J Pain Symptom Manage*. 2005;29:458-465.
36. Casarett DJ, Hirschman KB, Coffey JF, Pierre L. Does a palliative care clinic have a role in improving end-of-life care? Results of a pilot program. *J Palliat Med*. 2002;5: 387-396.
37. Brumley RD, Enguidanos S, Cherin DA. Effectiveness of a home-based palliative care program for end-of-life. *J Palliat Med*. 2003;6:715-724.
38. Jordhoy MS, Fayers P, Saltnes T, Ahlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. *Lancet*. 2000;356:888-893.
39. Santa-Emma PH, Roach R, Gill MA, Spayde P, Taylor RM. Development and implementation of an inpatient acute palliative care service. *J Palliat Med*. 2002;5:93-100.
40. Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care. *J Am Geriatr Soc*. 2007;55:993-1000.
41. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med*. 2004;164:83-91.
42. Hermerén G, Fleischhauer K. *Goals of medicine in the course of history and today: a study in the history and philosophy of medicine*. Stockholm: Kungl: Almqvist & Wiksell international. 2006.
43. Wright M, Wood J, Lynch T, Clark D. *Mapping levels of palliative care development: a global view. The International Observatory on End-of-Life Care*. England: Lancaster University. 2006.
44. Stjernswärd, J, Clark, D. Palliative medicine: a global perspective. In: Clark, D. ed. *Oxford textbook of palliative medicine*. Oxford, NY: Oxford University Press, 2004. 1199-1219.
45. Fisher C. The invisible dimension: abuse in palliative care families. *J Palliat Med*. 2003;6:2.
46. Harding R, Higginson I. Working with ambivalence: informal caregivers of patients at the end of life. *Supp Care Cancer*. 2001;9:642-645.
47. Kissane DW, Bloch S, McKenzie M, McDowall AC, Nitzan R. Family grief therapy: a preliminary account of a new model to promote health family functioning during palliative care and bereavement. *Psych Onc*. 1998;7:14-25.
48. Han PKJ, Arnold RM. Palliative care services, patient abandonment, and the scope of physicians' responsibilities in end-of-life care. *J Pall Med*. 2005;8:6.
49. Hanson LC, Henderson M, Menon M. As individual as death itself: a focus group study of terminal care in nursing homes. *J Pall Med*. 2002;5:1.
50. Morrison RS. Health care system factors affecting end-of-life care. *J Pall Med*. 2005;8(suppl.1):79-87.