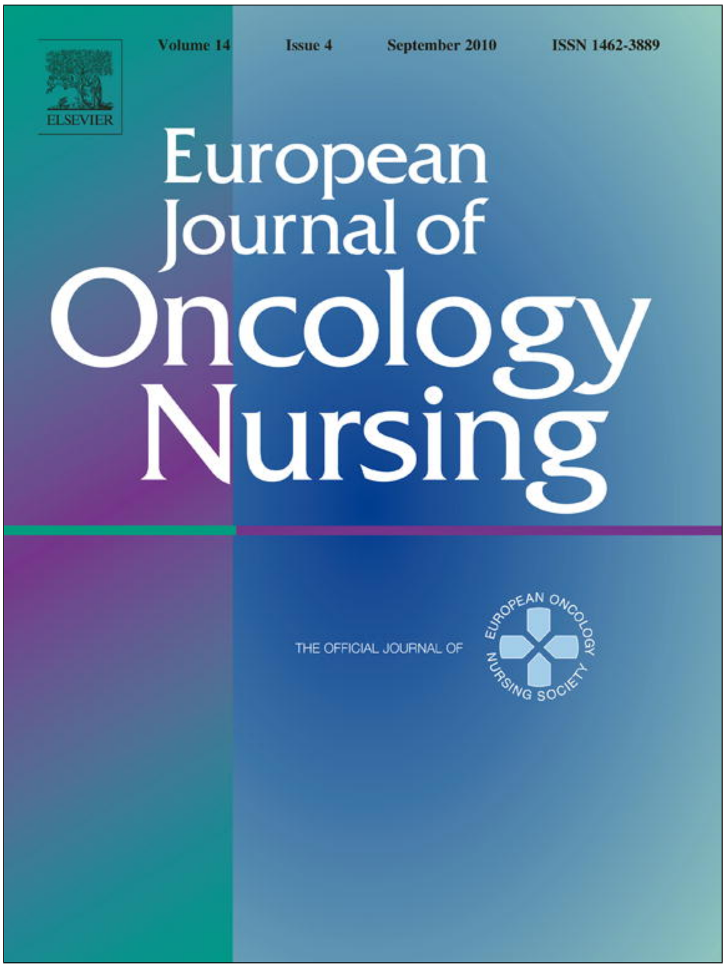
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End-of-life needs as perceived by terminally ill older adult patients, family and staff

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A B S T R A C T

Purpose of the study: A comparison of inpatient end-of-life needs as perceived by terminally ill older adult patients, family, physicians and nurses, is lacking. This study aimed to compare the importance attributed to different end-of-life needs by terminally ill older adult patients in long-term care facilities, their families and care providers (physicians and nurses).

Method: This descriptive, cross-sectional study recruited a convenience sample of 451 subjects, including 73 terminally ill older adult patients, 58 family members, 71 physicians and 249 nurses, from two Israeli geriatric centers.

Results: This study found a high congruence between the staff and terminally ill older adults and their families regarding most needs identified as important to dying people. The five needs identified as most important by all subjects were: not suffering pain, having no difficulty breathing, maintaining dignity, having someone who listens, and receiving adequate nursing care. The results of this survey suggest that for terminally ill older adult patients and their families, physical care is crucial. In contrast, nurses attribute higher significance to spiritual needs, but this finding may be affected by the fact that the rate of religiosity among nurses was much higher than among all other research groups.

Conclusions: Identifying terminally ill older adults' end-of-life needs may enable nurses and physicians to modify and improve end-of-life care. This could result in a substantial decrease in suffering amongst nursing home terminally ill older adult patients and their families.

Introduction

Improved medical technology over the last century has resulted in a significant increase in the human life span in general, and that of patients with chronic/life-limiting conditions in particular. Older adults who appear healthy usually do not die suddenly; most experience an age-related rise in incurable comorbidities, disability and suffering, for increasingly lengthy periods of time prior to death.

Comprehensive palliative care for dying patients presents the medical staff with unique challenges in providing physical, mental and spiritual care. Enhancement of the quality of care provided to dying patients is an issue currently awarded high priority in many health organizations worldwide (Singer et al., 1999). Most of those who require palliative care are older adults who have unique needs due to age variables, comorbidity, and extensive and sometimes exaggerated use of medication (Garfinkel et al., 2007). Many health care authorities believe that providing quality care to this population should be based on holistic individual guidelines (WHO, 2009). According to the holistic concept, older adults have multidimensional end-of-life needs: physical, emotional, social and spiritual. These needs may be categorized as follows:

Physical – a focus on balancing pain and other symptoms and on direct care.
Emotional and psychological– a focus on the ability to cope with a terminal illness, on personal and/or family problems deriving from the illness and on impending death.
Social– a focus on patients' interpersonal relations within the family, with society and their economic needs.
Spiritual– a focus on past experiences and the search for meaning in life and on religious and cultural ties (Steinhauser et al., 2000).

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The emotional and physical reactions of terminally ill older adults treated in long-term care facilities and those of their families, and staff responses to these needs are significantly interrelated. Lack of attention to any one of these needs could impact all the emotional and physical reactions of the dying patient and his/her family. In order to provide high-quality responses, it is necessary to assess all the patient's needs and understand their interrelated effects.

In order to improve the quality of care and its efficacy, it is necessary to begin by assessing patients' emotional, social and spiritual needs. This assessment is essential in order to construct a personal care plan adapted to the patient and his family's unique abilities and needs. It is essential to understand a family's perception of older adults' end-of-life needs since in many cases they will be in charge of determining the care policy of their family member. Failure to identify the family's values and their perception of the patient's essential needs could lead to inadequate patient care (Carlson, 2007).

One of the problems that can interfere with adequate care of dying patients at long-term care facilities, is that the care team might have a different outlook than the patient and his/her family regarding prioritization of end-of-life needs. In a study conducted by Flacker et al. (2001) physicians, nurses and aides were asked: what is most important to dying patients in the last three days of life? The areas examined were pain, comfort, emotional support, information, direct needs, supportive care and quality of death. The research results indicated differences between care team members: pain was perceived as more significant by aides than by nurses, physicians attributed the least significance to emotional support.

A study conducted at general Israeli hospitals among terminal patients and their families, found that despite expectations of patients and families to be involved in end-of-life dilemmas, in reality most of the decisions were made by the physician in charge with no structured involvement by nurses (Granot et al., 2002). In addition, the study found that the care provided to terminal patients did not include any discussion with patients on issues of life-sustaining efforts, while pain management was usually not exhaustive (Granot et al., 2002). Other studies found a lack of psychosocial support for patients and families and almost no support for the sorrow and grief of the family coping with the approaching death of their loved one (Stillman et al., 2005).

What are the possible reasons for identifying different needs by various care team members? One of the major reasons is professional training. There are essential differences between the professional training of nurses and physicians in regard to holistic perceptions of patients' needs. Murakawa and Nihei (2009) examined the meaning of the "good death" among physicians and nurses in Japan and found that nurses had better communication with patients. This was manifested in active listening, discussion of death and the provision of support, which were perceived by physicians as unimportant. In addition, physicians and nurses were found to differ even in their modes of communication with patients. While physicians would try to explain death, nurses would employ listening, support, and conversations with patients.

Palliative care training is needed to perceive patients' end-of-life needs. A study conducted in Denmark found that physicians and nurses who trained and worked in palliative care settings demonstrated a more positive approach compared to the staff of general hospitals. Nurses were found to be more emphatic with patients and their families on end-of-life issues than physicians (Vejlgaard and Addington-Hall, 2005). In other studies it was found that nurses trained in palliative care have higher awareness of patients' end-of-life needs compared to nurses with no training in palliative care. Nurses are more aware than physicians of the issue of death and of the significance of supporting patients and adapting care to their needs (Murakawa and Nihei, 2009)

Another significant variable is team members' cultural sensitivity towards terminal patients. Patients who come from different cultures and have different customs regarding death than those of care providers, do not receive adequate responses to their individual needs, particularly spiritual needs (Kayser-Jones, 2000; Pleschberger, 2007). Although the nursing staff recognizes patients' spiritual end-of-life needs and attempts to provide for these needs through personal care, they realize that their resources are insufficient due to time constraints, cultural differences, and conflicts regarding personal beliefs (Pleschberger, 2007).

This research does not indicate which elements of the holistic theory should serve as the focus of end-of-life care, and whether the care team (physicians and nurses) perceives needs differently than family and patients. The current study highlights these issues.

Methods

Sample and setting

This descriptive, cross-sectional study used a convenience sample. Participants included terminally ill older adult patients, their families, physicians and nurses at Israeli geriatric centers. Staff eligibility criteria included being a nurse or physician at a geriatric medical center, being able to read and write in Hebrew, and having cared for terminal patients. Patient and family eligibility criteria were end-of-life patients residing at a geriatric center and family of end-of-life patients who speak and read Hebrew and are able to communicate.

Research tool

The current study used a questionnaire adapted from that proposed by Steinhauser et al. (2000) which was based on focus groups and interviews with patients, families, physicians and other staff members. The questionnaire consists of 43 needs which participants were asked to rank according to their importance to people at the end of their life. Items were ranked on a 5-point Likert scale: 1– strongly disagree, 2– slightly agree, 3– moderately agree, 4– greatly agree and 5– strongly agree. Patient needs focused on five categories: physical, emotional, psychological, social and spiritual. In addition, there were 17 questions on subjects' socio-demographic and professional background. The questionnaire was translated into Hebrew and translated back into English in order to confirm translation validity. Three geriatric nurses and 3 geriatric physicians performed an internal validity test. Consequently, the Hebrew phrasing of several parameters was adjusted. Then a pilot questionnaire was distributed to 20 nurses, 10 family members and 10 patients. The level of reliability, Cronbach alpha of the questionnaire, was set at 0.75–0.85.

Procedure and ethical considerations

The study was reviewed and approved by an institutional review board. Nurses and physicians meeting the inclusion criteria were recruited at staff meetings at the major geriatric center involved. Additional physicians from other centers were recruited by flyers advertising the research, asked to complete the survey at a convenient time and return it to the data researcher at the major geriatric medical center. The researchers directly approached terminally ill patients and their families at the major geriatric center at the direction of head nurses of the different departments and asked for their consent to complete the questionnaire.

The main part of the survey was preceded by an information sheet clearly outlining the purpose of the study and stating that participation was strictly voluntary and could be discontinued at any time. Completion of the questionnaire required approximately 25 min. Completion and return of the survey indicated the informed consent of the participant. Five hundred and fifty questionnaires were distributed, and 451 completed surveys were returned, indicating an 82% response rate.

Data analysis

The data was analyzed using SPSS statistical software (Version 12.0; SPSS Inc., Chicago, IL, USA). Descriptive statistics were employed, including means, standard deviations, percentages and ranges of the research variables. One-way analysis and Scheffe post hoc tests were used to examine differences between the groups.

Results

Of the 100 terminally ill older adult patients requested to participate in the study, 73 completed the questionnaire (73% response rate), and of the 70 family members 58 responded (82% response rate), as did 71 of the 75 physicians (94% response rate) and 249 of the 260 nurses (95% response rate).

Most of the participants (302, 66.6%) were women. Most of the subjects were Jewish (376, 83.4%), not religiously observant (238, 52.7%), married (281, 62.3%), with an average of 2.7 children (standard deviation 0.9 and range 1–5). Most of the nurses were registered nurses with an academic degree (108, 58.1%). Most of the physicians specialized in internal medicine (40, 56%) and geriatric medicine (33, 46%). Most of the family members were sons and daughters of the patients (37, 63%).

The five needs stated as most significant by all research participants were in descending order: 1. Absence of pain ($M = 4.93$; SD = 2.4); 2. Maintaining dignity ($M = 4.9$; SD = 2.42); 3. Attentive staff ($M = 4.61$; SD = 0.6); 4. Feeling comfortable with the nurse ($M = 4.60$; SD = 0.5); 5. Prevention of respiratory difficulties ($M = 4.59$; SD = 2.4). Over 60% of the patients were not interested in using all means to prolong their lives, including artificial feeding and respiration, when there was no potential cure. Of all patients, 86.4% would want to know the truth about their condition and 57% would wish to die at home.

Significant differences were found in the perceptions of the research sub-groups regarding 13 needs (Table 1). One-way analysis of variance with Scheffe post hoc test found that elderly patients attribute more significance than physicians and nurses to the following needs: remaining conscious, discussing fears, telling the truth and ability to help others ($p < 0.01$). Patients also attribute more significance than physicians to the need to include them in determining the care policy ($p < 0.01$). In addition, family members and patients attribute more significance than medical and nursing staff to updating patients and families regarding patients' medical condition ($p < 0.01$). Nurses attribute more significance than patients, families and physicians to being at one with God, praying and conversation with a cleric about the meaning of death ($p < 0.01$). Examination of the research population's demographics shows a significant difference in the level of religiosity (χ^2 (9) = 20.3, $p < 0.01$). Fifteen percent of the nurses were religious, versus the other research groups (physicians, family members, patients) of whom only some 7% were religious.

One-way analysis of variance of all needs showed a significant difference in subjects' perception of spiritual needs ($F(3,447) = 5.7$, $P < 0.01$) and physical needs ($F(3,447) = 5.8$, $P < 0.01$) (see Table 2). A Scheffe post hoc test found that patients attribute more significance to physical needs than physicians and nurses ($p < 0.01$) (see Fig. 1).

Discussion

The current study found a high level of congruence between the staff (physician, nurse) and terminally ill older adult patients and their family regarding most needs identified as important to terminal patients. The five needs identified by participants as most important were: not suffering pain, no difficulty breathing, maintaining dignity, having someone who listens, and adequate nursing care.

Pain and dyspnea are the symptoms most frequently discussed in the literature, and this corresponds with the high level of distress they impose upon patients, families and care providers. When pain and dyspnea are well controlled, palliative care is considered highly successful (Raudonis et al., 2002). Several international studies have found that the main problem regarding these issues is that nurses lack information about pain assessment and the relief of pain and dyspnea (Ferrell and McCaffery, 1997; Field and Cassel, 1997).

The most interesting findings of the study are probably related to items for which wide variations in responses were found within and across all sub-groups. They serve as a reminder that nowadays there is no single acceptable definition of end-of-life needs. Good-quality end-of-life care seems to be a dynamic process requiring the

Table 1
One-way analysis of variance for detecting differences between the perceived needs of the various research groups.

Need	Patients $N = 73$	Family $N = 58$	Nurses $N = 249$	Physicians $N = 71$	F	p
Physical needs						
Maintaining hygiene	4.6	4.3	4.4	4.7	4.6	0.003
Release from breathing difficulties	4.7	4.6	4.5	4.4	3.0	0.02
Remaining conscious and clearheaded to the end	4.4	3.2	3.5	4.1	17.2	0.001
Physical independence to the end	4.3	3.2	3.6	3.7	3.5	0.002
Emotional needs						
Regular update on medical condition	4.6	4.6	4.0	4.0	15.7	0.001
Opportunity to discuss fears and anxieties	4.7	4.5	4.5	4.3	6.2	0.001
Telling the absolute truth to patients	4.5	3.8	3.8	4.0	8.8	0.001
Involving patients in care policy and decisions	4.6	4.5	4.2	3.8	2.7	0.05
Spiritual needs						
Being at one with God	3.5	3.3	3.8	3.4	3.6	0.01
Praying	3.2	3.1	3.6	3.1	3.8	0.009
Conversation with cleric about meaning of death	2.7	2.6	3.1	2.5	4.2	0.005
Social needs						
Capacity to help others	4.4	3.2	3.3	3.7	18.4	0.001

Df = 4, 430

Table 2
One-way analysis of variance for detecting differences between the physical and spiritual needs of the various research groups.

Need	Patients	Family	Nurses	Physicians	*F*	Sig
Physical needs	4.1	3.9	3.8	3.7	5.8	0.000
Spiritual needs	3.4	3.2	3.7	3.2	5.7	0.001

health care professional's knowledge and common sense, along with constant and strict cooperation with patients and families. The process is mediated by the individual's and family's values, knowledge and care preferences. The disinclination of physicians and other care providers to use all available treatments may reflect their greater familiarity with life-sustaining treatments. Patients were found to be less likely to consent to carediopulmonary resuscitation after receiving additional information about the procedure (Brazil et al., 2005; O'Brien et al., 1995; Steinhauser et al., 2000).

Considering the strong public support for the hospice movement and its emphasis on home care, we expected to find a significantly high preference for dying at home (National Hospice Organization, 1996). However, as most symptoms are usually significantly aggravated in the last 24–48 h before death, some patients and families may fear the devastating impact of these symptoms and feel overwhelmed by concerns about symptom control or the presence of "a dead body at home" and therefore prefer an institutional skilled care environment. Therefore, although for many patients an appropriate goal would be to allow them to die at home, it should not be automatically assumed that all patients and families would prefer this option.

Terminally ill older adult patients wish to remain active and continue most of their previous life roles during the end-of-life period. They want to continue contributing to the care of their family and significant others, and they would like others to respect their autonomy. In essence, they want to continue living while in the process of dying (Singer et al., 1999).

Our findings demonstrate that patients prefer truthful information even at the terminal stages of their disease and this is consistent with several other international reports (Schofield et al., 2006). For example a survey among terminal patients in Belgium concluded that truthful communication was the most important factor in decision making during the end-of-life stage (Deschepper et al., 2006).

The wish to receive medical information about the patient's condition was ranked by families as more significant than by staff. This finding is compatible with that of Ben Natan (2008) who found that providing information enables family members to be involved in therapeutic decisions related to terminal patients.

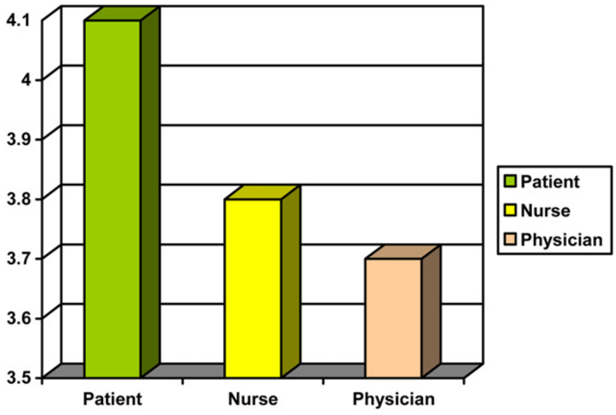

Fig. 1. Differences between patients, nurses and physicians in the identification of physical needs.

Limitations

This study has several limitations. Although participating staff members belonged to several geriatric centers, patients and family members were recruited from a single geriatric medical center, and therefore one should be very cautious in generalizing these conclusions to other groups or settings.

The sample of older adults and their families was relatively small and using it to reach conclusions regarding other subgroups of older adults is problematic, thus precluding generalization. However, our main findings seem valid and certainly deserve further and larger studies in other settings caring for older adults.

Conclusions

The results of this survey suggest, as expected, that for patients and families, end-of-life physical care is perceived as crucial. Our results indicate that end-of-life patients in long-term care settings wish to be much more involved in their own personal care and in the planning of everyday life at the nursing home. In contrast, nurses attribute higher significance to spiritual needs, although this finding may be affected by the fact that the rate of religiosity among nurses was much higher than among all other research groups.

Quality care at the end-of-life is highly individual and should be achieved through a process of shared decision making and clear communication that acknowledges the values and preferences of patients and their families. It is essential that nurses put forth sustained effort in working to improve end-of-life care.

Conflict of interest statement

The authors declare that there are no conflicts of interest.

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