Family Experiences in End-of-Life Care: A Literature Review

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Purpose  The purpose of this study was to summarize and analyze families’ experiences of end-of-life care by conducting a systematic review of peer reviewed journals both in Korea and abroad.

Background  Families play an increasingly important role in care and medical treatment, acting as caregivers or decision makers rather than just being passive observers. It is necessary to understand the experiences of family members in order to provide appropriate care for them.

Methods  A systematic search of the literature was performed using the Cumulative Index for Nursing and Allied Health Literature (CINAHL) and the Korea Education & Research Information Service (KERIS) for the period of January 1990 through to December 2006. A total of 35 studies met the inclusion criteria.

Results  Seventeen studies used a quantitative design, while 18 studies used qualitative methods. Quantitative studies reported that the family's quality of life was relatively low when the patient was in need of high medical/nursing services. The perceived burden levels were moderately high, and depression levels were high among family caregivers. Various concepts emerged from the 18 qualitative studies, including psychological issues, physical problems, burdens, needs and interpersonal relationships.

Conclusion  This study found that most previous research findings were focused on negative and neutral experiences. A few studies identified positive experiences. Based on the study results, we suggest that nurses need to be more aware of the experiences of patients’ families and their potential needs. [Asian Nursing Research 2008;2(4):223–234]

Key Words  family, literature review, terminal care

INTRODUCTION

Patients in end-of-life (EOL) stages are increasingly staying in hospitals until death because they need specialized treatment and care. In Canada, 73% of the entire population eventually ends life in hospital. A total of 20% die in intensive care units (ICUs) located in hospitals (Heyland, Rocker, O’Callaghan, Dodek, & Cook, 2003). In the UK, 60% percent of all deaths occur in hospitals (Main, 2002). In Korea, traditionally all the family members and relatives gather to witness the passing of a loved one and to participate in the funeral. As Korean society undergoes increased economic development, more and more people are dying in hospitals or institutions (Choi, 2004). Therefore, spending time until the EOL in hospitals or institutions is not unusual; this highlights a need for good quality care until the EOL for patients and their family members.

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Received: August 27, 2008  Revised: September 12, 2008  Accepted: November 21, 2008
In terms of EOL care, healthcare professionals have focused more on patients than on their family members (Fox-Wasylyshun, El-Masri, & Williamson, 2005; Lee, 2001; Main, 2002). Researchers have also focused on EOL patients, with only a few consulting family members and surveying their experiences (Sung, 1996).

Lee (2001) highlighted nurses’ potential for assisting families of patients in EOL care since families are not just passive observers but play an active, important part in EOL patients’ care and medical treatment by acting as caregivers and decision makers. The inability of a family to cope with an EOL patient may lead to family dysfunction that could negatively impact on patient recovery (Fox-Wasylyshyn et al., 2005). Nurses should understand families’ attitudes toward death and feelings such as fear, panic, and anxiety within the family, because these can directly affect patients’ medical progress or condition (Ha, 2004; Sung, 1996). Therefore, it is important to understand what families experience during EOL care in order to provide appropriate care to patients and their families (Verhaeghe, Defloor, Zuuren, Duijnste, & Grypdonck, 2005).

Previous articles reviewed included a study on the family in EOL care in ICUs (Azoulary & Pochard, 2003; Kirchhoff, Song, & Kehl, 2004), a study concerning the family in EOL care in pediatric ICUs (Copnell, 2005), and a study dealing with the needs and situations of families (Andershed, 2006; Thielemann, 2000). These studies had limited scope, making it difficult to gain a full understanding of family experiences in EOL care.

This study aimed to determine and analyze what families in EOL care experience by reviewing relevant studies in academic journals both from Korea and abroad, while providing basic information for nurses’ education and practical care of patients and their families in EOL situations.

BACKGROUND

Characteristics of families in EOL care
Everyone can experience the moment when one of his or her family dies. Such a death can be a significant factor in destroying the way a family functions and can also generate deep shock (Kim, 1992). In Asian countries, where the basic unit of society is not a person but a family group, a patient’s disease creates visibly high anxiety levels within the family system, and can change relationships, roles, or communication between family members. It affects the lives of all family members (Lee, 2001). In Korea, there is no fully implemented hospice system for patients in the EOL, and hospice facilities and care assistants are not adequately supported. Therefore, family members care for the patient requiring EOL care during their hospital stay (Lee, 2001; Lee, 2005). This can mean long-term care and may also include specialized care (Lee, 2001).

With EOL care, family members have to face new challenges that may potentially be above and beyond their ability to adapt to, including financial difficulties, role changes within the family, sexual problems, and changes in the overall health condition of other family members (Hwang, 2000). For example, patients may have emotional problems such as sadness, anxiety, fear, and depression, and physical problems such as tiredness and exhaustion (Lee, 2005).

These problems can lead to family dysfunction if family members are not well prepared for such physical, emotional, and economic challenges. According to Ha (2004), the overall quality of life experienced by terminal cancer patients and by their caregivers is interrelated: if the former improves, the latter improves. Emotional problems such as anxiety, fear of sudden death, depression, and feelings of loss, which family caregivers experience during the care process, affect the patients as well as all the other family members. Therefore, nurses should regard the other family members not only as a supportive resource, but also as quasi-patients. Family caregivers’ problems should be identified and dealt with as part of the family’s problems (Kim, 1992). Nurses should perceive families in EOL care as important subjects for care and should take an active role in supporting them emotionally, and helping them deal with stress or difficult situations more efficiently (Fox-Wasylyshyn et al., 2005).
The importance of identifying the experiences of families in end-of-life care

It is necessary to understand what the experiences of family members actually are in order to provide proper and satisfying care for the families of EOL patients. While families want nurses to explain the patient’s prognosis and associated care strategies, nurses may underestimate the needs of these families (Verhaeghe et al., 2005). In a study by Dockter et al. (1998), nurses were not willing to allow family members to participate in the care of patients, and they thought that family members did not have enough time to visit their loved ones. However, family members wanted to inquire into the patient’s condition, but they often did not ask due to anxiety or worry. Wagner (1996) suggested that family caregivers understand their loved ones’ needs better than nurses do. Family members perceive a need for information and value patients’ comfort more highly than nurses do. By helping nurses understand how family members react to the EOL situation, nurses should be able to pay attention to the needs and requests of family members to bring about positive responses and increased satisfaction levels (Eom, 2001; McIntyre, 1997).

METHODS

Search methods

A systematic search of related literature was performed using the Korea Education & Research Information Services (KERIS) and the Cumulative Index for Nursing and Allied Health Literature (CINAHL), for the period from January 1, 1990 to December 31, 2006. The search results included qualitative and quantitative studies examining the experiences of families of patients in EOL care.

The inclusion criteria were defined as follows:
(a) Within the KERIS, the search was restricted to studies published in the Korean language, using the following Korean search words and phrases: families in end-of-life care; families of terminal patients; families of terminal cancer patients; families of hospice patients.
(b) Within the CINAHL, the search was restricted to studies published in the English language, using the following combinations of terms: experiences, needs or problems; families of dying patients; families of terminal patients.
(c) All studies used were published in peer-review journals.

The exclusion criteria were defined as follows:
(a) Studies related to the experiences of the patients’ family members at the moment of death resulting from sudden illnesses and accidents, such as traffic accidents.
(b) Studies on ethical issues such as euthanasia and withholding/withdrawing treatment.
(c) Studies examining the effects of a specific nursing intervention.
(d) Studies involving patients at the EOL under 18 years old.
(e) Studies conducted for Masters or Doctoral degrees that were not published in a peer review journal.

Search outcome

There were no search results using the key phrase ‘family in end-of-life care’ in the KERIS database. However, it was discovered during the search process that the keyword ‘dying’ is more frequently used than the keyword ‘end-of-life’ in Korea. When the phrases ‘dying’ and ‘families of dying patient’ were added to the list a total of 56 studies were retrieved from the KERIS. Initially 21 studies were selected following the inclusion criteria. Among these studies, 15 studies that were not published in academic journals were excluded, and the remaining six studies were selected for the final analysis.

The search of the CINAHL database was performed using the following combinations: experiences, needs or problems; families of dying patient or families of terminal patient; not interventions; not euthanasia or withholding or withdrawing treatment; not sudden accident or disease; and not child. The searches were restricted to studies published in English for the period from January 1, 1990 to December 31, 2006. With these limitations, 945
studies were identified. Following our inclusion and exclusion criteria, a total of 29 studies were selected.

RESULTS

Research design and research trends by year
The overall research design and research trends by year were summarized in Table 1. There were 17 quantitative and 18 qualitative studies. Among the quantitative studies, six were conducted in Korea, while 11 took place in foreign countries. All qualitative studies were completed in foreign countries. Only one study was published in the early 1990s. However, since the mid 1990s, researchers’ interest in this topic has increased steadily.

Most quantitative studies used survey type research, whereas various methods, including phenomenology, ethnography, and grounded theory methods, were used in the qualitative studies.

A summary of quantitative studies
Among the 17 quantitative studies, seven studies concerned nursing needs, five involved burdens, and the others were related to a variety of themes such as quality of life, coping strategies, interests, stress factors and tension, depression, present problems, and overall spiritual well-being. In the Korean studies, 70–153 participants were surveyed, while the numbers of people surveyed in foreign studies ranged from 20–206. In the Korean studies most caregivers were in their 30s and 40s, while in foreign studies caregivers were mainly in their 50s and 60s.

In the suggested research results, the nursing needs of family caregivers related to information, useful resources, emotional support, spiritual support, and guidance about their roles were high (Chung & Kim, 2003; Kim, 1998; Lee et al., 1998; Lin & Tsao, 2004; Newton, Bell, Lambert, & Fearing, 2002; Osse, Verooij-Dassen, Schadé, & Grol, 2006; Steele & Fitch, 1996a).

Burdens on families were moderately high. Overall, the burden was more prevalent in families of patients with multiple symptoms or higher activities of daily living needs and in families with more limited social networks (Andrew, 2001; Chang & Lee, 2000; Chung & Kim, 2003; Given et al., 2005; Goldstein et al., 2004).

Quality of life levels were comparatively low. Specifically, levels of quality of life regarding economic status and emotional state were lower than those regarding self esteem, physical function or family relationships (Kim, 1997; Ro & Kim, 1998).

The most common coping strategies were keeping busy, having a sense of humor, thinking positively,
and changing one’s mood by doing something that the person liked (Steele & Fitch, 1996b).

The important elements of EOL care from the family’s perspective related to trust in the treating physician, avoidance of unwanted life support, and effective communication (Heyland et al., 2006).

Family members reported high levels of depressive symptoms (Given et al., 2005). Moreover, tension levels in families of EOL patients were higher than those of families of older patients with chronic disease (Redinbaugh, Baum, Tarbell, & Arnold, 2003). Families spent more than 12 hours caring for patients daily (Newton, Bell, Lambert, & Fearing, 2002).

Spiritual well-being in family members was low (Sherman et al., 2005).

A summary of qualitative studies
During the search process of Korean qualitative studies, six studies were identified. However, they were excluded because they were unpublished manuscripts and did not meet the inclusion criteria. Since 1995, studies related to EOL care have been published every year at a steady rate. Most of the studies looked at caring experiences, and they also discussed coping strategies or responses. There was one study that focused mainly on hope, which was viewed as a positive concept. These research projects involved 5–70 mainly middle-aged and elderly subjects.

From the research results, 99 different concepts were identified. Grouping similar ideas yielded a new total of 49 concepts. These were divided into six types of experience: psychological/emotional experiences; interpersonal experiences; physiological experiences; burdens; needs; and other (i.e., funeral service issues and preparation for death).

Finally, we sorted the concepts into three main categories according to Hunt’s (2003) classification system: positive experiences, negative experiences, and neutral experiences (Table 2). Hunt clarified concepts for nursing research and practice when the family is providing care to chronically ill patients. Positive concepts included caregiver esteem, uplifting moments in caregiving, caregiver satisfaction, finding meaning through caregiving, and gain in the caregiving experience. Negative concepts included caregiver burden, hassles, strain, and stress. A neutral concept is caregiver appraisal about the caregiving situation. Hunt identified needs as one of the most effective tools used in appraisal.

There were two subcategories in the positive experiences category: psychological/emotional experiences and interpersonal experiences. In the positive psychological/emotional experiences category, the most frequent concepts were ‘commitment’ and ‘perceiving oneself as a person who is essential to the patient’, which were each dealt with in five studies. Hope-related concepts such as ‘holding onto hope for a miracle’, ‘trying not to lose hope’, and ‘believing in recovery’ were the next most frequently considered concepts, discussed in four studies. Other concepts were ‘appreciation’, ‘managing oneself’, and ‘personal growth after reflection’.

The most frequently described positive interpersonal experiences were ‘greater closeness to the patient’ and ‘opportunity for showing love’. The second most frequent concepts were ‘recovering relationships with other family members after sharing patient care’ and ‘feeling respected by the health care provider’. ‘Getting support from social network for coping’ was identified in two studies.

There were four subcategories in the negative experiences category: psychological/emotional experiences; physiological experiences; burdens; and interpersonal experiences. Among the negative psychological/emotional experiences, the most frequent concept was ‘exhaustion/tiredness,’ which was dealt with in eight studies. Other frequently described concepts were ‘loneliness’, ‘powerlessness’, ‘fear’, ‘uncertainty’, ‘surprise’, ‘anger’, ‘stray and anxiety’, ‘social isolation’, ‘regret’, and ‘intolerance’.

It was noticeable that these subjects’ physiological experiences also had a negative impact. The most frequent negative physiological experiences were ‘sleep disturbance and a lack of sleep’. The next most frequent concepts included ‘fatigue’, ‘indigestion’, and ‘a general state of poor health’.

In the burden subcategory of the negative experiences category, ‘the burden of time’ was the most frequently discussed concept. The next most frequent was ‘financial burden’, which was dealt with in
<table>
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<tr>
<th>Categories</th>
<th>Subcategories</th>
<th>Concepts</th>
<th>Frequency&lt;sup&gt;a&lt;/sup&gt;</th>
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<td>Psychological experiences</td>
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<td>Perceiving oneself as a person who is essential for the patient</td>
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<td>Holding onto hope for a miracle/Trying not to lose hope/Believing in recovery</td>
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<td></td>
<td>Appreciation</td>
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<td>Managing myself/Taking care of myself/Giving comfort to myself</td>
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<td></td>
<td>Personal growth after reflection</td>
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<td>Interpersonal experiences</td>
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<td>Greater closeness to patient/opportunity for showing love</td>
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<td>Recovering relationships with other family members after sharing patient care</td>
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<td>Feeling respected by health care provider</td>
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<td>Getting support from social network for coping</td>
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<td>Psychological/Emotional experiences</td>
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<td>Loneliness</td>
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<td>Fear</td>
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<td>Uncertainty of life situation</td>
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<td>Surprise/Shock</td>
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<td>Strain &amp; anxiety</td>
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<td>Grief/Loss</td>
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<td>Guilt</td>
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<td>Fatigue</td>
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<td>Indigestion/Loss of appetite/Heartburn</td>
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<td>Financial burden</td>
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<td></td>
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<td>Social burden: decreased social activity and limited social network</td>
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<sup>a</sup> Frequency indicates the number of times the concept was identified across the qualitative studies.
six studies. Other concepts included ‘burden related to limited social activity’ and ‘physical burden.’ The concept ‘burden related to personal growth’ was analyzed in one study.

In the negative interpersonal experiences subcategory, the most frequently discussed concept was ‘role change/difficulty in doing two jobs: managing the household and caring for the patient.’ The second most frequent concept was ‘increased responsibility/family support conflict.’ The second most frequent concept was ‘increased responsibility/family support conflict’ followed by ‘communication problems with health care personnel’. Others were ‘restriction from telling the truth to the patient,’ which was found in six studies, and ‘reluctance to disclose their situation to others or not wanting to be helped,’ which was reported in three studies.

There were three subcategories in the neutral experiences category: psychological/emotional experiences; family needs; and other experiences related to administrative procedures. In the neutral psychological/emotional experiences, there were concepts related to evaluation of the present situation. These were ‘living with thinking about the fact that patient is alive,’ ‘finding comfort in religion,’ and ‘acceptance of the present situation.’ In the family needs category, the most frequently described concept was ‘need for information regarding the patient’s condition, treatment, and care.’

### Table 2 (Continued)

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<td>Restriction from telling the truth to</td>
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<td>the patient is alive</td>
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<td>Dependence on religion</td>
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<td>Useful resources</td>
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<td>Other</td>
<td>Funeral service issues/ preparation for death</td>
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condition, treatment, and care.' The second most frequent concepts were ‘guidance about roles’ and ‘useful resources (housework support, financial support, and counseling about legal issues).’ Other neutral experience concepts such as ‘family’s interest in alternative therapies,’ and ‘spiritual/emotional support’ were identified. Family experiences related to funeral services or ‘preparation for death’ was mentioned in five studies.

**DISCUSSION**

Since the 1990s, interest in issues relating to EOL care has increased and researchers have started to look at a patient’s family as quasi-patients. Studies, using various research methods, on the families of EOL patients have been steadily increasing in number. However, only 35 studies were analyzed in this study, a small number compared with other similar studies (Andershed, 2006; Verhaeghe et al., 2005). The reason for the limited number of studies is that most Korean studies were written for Masters or Doctoral theses and were not published. Furthermore, a limited number of foreign studies were considered because the CINAHL database for nursing-related papers was the only search engine available. Additionally, studies using triangulation methods were not included in the analysis because the content of these studies was similar to that of the quantitative and qualitative studies selected in this study; such studies were not deemed very influential for the purpose of this study. This exclusion was considered to be another limitation in this study.

As shown in 17 quantitative studies, most EOL patients’ families tended to be middle-aged or elderly; spent more than 12 hours a day caring for patients; and experienced a low quality of life, a high level of burden, and depression, which indicated that more comprehensive and diverse kinds of support and interventions were needed.

The research tools used in the quantitative studies were mostly reliable. It was interesting that these studies used different tools to measure the same variables. For example, various tools such as the Zait Burden Inventory (Chang & Lee, 2000; Goldstein, 2004), Seo and Oh’s Burden Measurement Tools (Chung & Kim, 2003), and the Caregiver Reaction Assessment and Caregiver Burden Screen of Given et al. (1992) (Andrews, 2001; Given et al., 2005; Redinbaugh et al., 2003) were used to measure burden. However, the items in these questionnaires were different. Cultural background should be considered when analyzing family burdens. It is also necessary to develop and apply standardized tools for surveying EOL patients’ families in order to compare and analyze family burdens more closely.

Many themes analyzed in the quantitative studies such as ‘family’s quality of life’, ‘nursing needs’, ‘stress’, ‘depression’, ‘spiritual well-being’, and ‘problems’ mainly focused on negative or neutral experiences. However, many positive experiences have been identified from qualitative studies. According to Kramer (1997), the richness of qualitative data indicates that quantitative instruments might be limited in assessing positive experiences. Therefore, if researchers intend to identify care experiences from a more holistic perspective, they should measure the positive aspects of care in future studies.

In a study by Hunt (2003) involving family care, positive experiences, negative experiences, and appraisal were equally emphasized. Positive experiences suggested in the qualitative studies reviewed in this analysis were similar to those described by Hunt. For example, ‘perceiving oneself as a person who is essential for the patient’ indicated recognition of one’s existence as well as satisfaction. It was similar to the concept of ‘self-respect as a caregiver,’ which was mentioned in the study by Hunt. The concept of ‘personal growth after reflecting on life’ was similar to the ‘search for the meaning of life through caring’ discussed by Hunt. Positive interpersonal experiences such as ‘recovering relationships with other family members after sharing patient care,’ ‘feeling respected by the health care provider,’ and ‘support from a social network’ were similar to the concept ‘positive experience from using a caregiver’s resources through care’ (coping and social support) in the study by Hunt. Many of the qualitative studies
in this review reported that formal and informal support networks were considered valuable systems for effective coping with the overwhelming process of care (Enyert & Burm, 1999; Holtslander, Duggleby, Williams, & Wrighty, 2005; Perreault, Forhergill-Bourbonnais, & Fiset, 2004; Stajduhar, 2003; Woodhouse, 2004). This indicates that social support, where health care providers recognize and respect the patient's family as caregivers, can be an important factor in achieving positive experiences for the patient's family.

Negative experiences analyzed in qualitative studies were similar to those described in the existing review studies related to EOL care (Hunt, 2003; Verhaeghe et al., 2005). These negative experiences correspond to the results of the quantitative studies analyzed in this study. For example, 'burden of time', mentioned in seven qualitative studies, is related to 'spending more than 12 hours per day on patient care', which was the most commonly cited result in quantitative studies. Most negative experiences were related to a lack of support from other family members or from the patient's social network. More specifically, 'role change/difficulty in doing two jobs: household work and patient care,' 'communication problems with health care personnel,' 'increased responsibility/family support conflict,' 'loneliness' and 'social isolation' were mentioned in most of the qualitative studies, which highlighted the necessity for social support networks. Mangan, Taylor, Yabroff, Fleming, and Ingham (2003) described the usefulness of family and community support in easing the emotional burden of caregiving. Therefore, strategies are needed to determine how social support can be planned effectively for EOL patients' family interventions.

Neutral experiences cited in qualitative studies reviewed mostly involved family needs. These needs were related to helpful methods and to the use of resources for patient care. The most frequently mentioned family needs were information about the patient's condition and guidance about their role. This demonstrates why healthcare professionals should provide, in an open-minded manner, adequate information in accordance with patients' family needs. These experiences are supported by the results of other existing review studies about care (Andershed, 2006; Verhaeghe et al., 2005).

**CONCLUSION**

Most of the studies related to the EOL patient's family reported negative experiences such as 'burdens,' 'depression,' 'exhaustion/tiredness' and neutral experiences such as 'family needs'. However, some positive experiences such as 'hope,' 'commitment,' 'opportunity for showing love,' and 'reflecting on life' were identified in other studies. This indicates that assessments regarding family experiences and needs should be performed in reference to a variety of aspects and in a more careful and cognitive manner.

Many negative experiences analyzed in this study were related to a lack of social support. However, in the case where patient-care duties are shared among family members and enough social support is provided, the family tends to have a positive experience such as 'recovering relationships', suggesting that efficient interventions to facilitate social support are necessary.

Communication problems with health care providers, family needs related to information about the patient’s overall condition, and guidance about the family’s role – mentioned in many studies – lead us to feel that nurses have a great deal of responsibility in achieving positive outcomes. Nurses should respect and support the patient’s family members as caregivers, should listen to them in an open-minded manner, and meet their concerns. Nurses should always remember that this is a basic duty, which eventually has a positive influence on both the EOL patient and the patient’s family.

Last, the authors suggest developing standardized tools for measuring experiences of EOL patients' families in future studies. Additionally, it is necessary to identify which of the families' characteristics are related to positive versus negative experiences, in order to strengthen positive aspects and minimize negative aspects involved in the process of patient care.
ACKNOWLEDGMENTS

This study was funded by Nursing Policy Research Institute, College of Nursing, Yonsei University Grant.

REFERENCES


**APPENDIX: STUDY LIST MET THE INCLUSION CRITERIA**


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