





REVIEW

Family members' participation in palliative inpatient care: An integrative review

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Abstract

Aim: To analyse how family members participate in hospital inpatient palliative care, and how their participation could be supported.

Methods: This review followed a methodology outlined in the literature for integrative reviews. A literature search supplemented by a manual search was conducted on four electronic databases during 2020 to 2021: PubMed, CINAHL, PsycINFO, and Cochrane Library. A critical appraisal of the included studies was performed, and data were analysed using inductive content analysis.

Results: The literature search resulted in 4990 articles, of which 14 articles were included in this review. Four main categories were identified concerning the participation of family members in hospital inpatient palliative care: participation in the physical care, provision of emotional support, promoting good patient care, and support provided by healthcare professionals for family members' participation. Family members' participation can be supported in different ways, including active communication and adequate information.

Conclusion: Family members' participation in hospital inpatient palliative care has been an important part of palliative care in hospital settings. Family members should be offered the opportunity to participate in patient care, and their presence in the hospital should be accommodated. Research on the topic is still scarce, and future research is needed from different perspectives, including intervention research.

KEYWORDS

family member, hospital, literature review, palliative care, participation, patient care

INTRODUCTION

Palliative care concerns patients and their family members, and the whole family forms the unit of care. It has been estimated that more than 50 million people worldwide are

in need of palliative care each year, most of them being adults [1]. In Europe, it was estimated that in 2014, more than 4 million people were in need of palliative care [2]. This means that many family members are also affected by palliative care. Palliative care can be provided in different

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settings. In this review, the focus is on the hospital inpatient setting, where it is common for patients to be treated at the end of life [3], usually because of different symptoms and poor management of these symptoms [4].

The importance of family caregivers has been highlighted by the European Association for Palliative Care [5, 6]. In the code of ethics for nurses [7], the role of family members' and nurses' responsibility in promoting a respectful environment for both the patient and the family has been noted [7]. Also, in previous studies, the involvement of family members has been identified as an important part of end-of-life care in the hospital environment [8, 9]. Patients need support from their family members, and the participation of family members positively affects the feeling of loneliness [10]. Family members' participation in the care increases the quality of patient care [11] and supports the well-being of the family members [12], and it is therefore important that healthcare professionals allow family members' participation [13]. In many European countries, palliative care is guided by national legislation. In addition, some countries have national guidelines for palliative care [1] and also the role of family members has been noted [14]. Because patients might have different preferences regarding the actual participation of their family members [13], the opinion of patients needs to be considered [15].

In the study of Cohen et al. [16], the results showed that family members of patients receiving end-of-life care spent more days with the patients in hospital compared with family members of acutely ill patients, and they are dedicated in their role. Family members play an important role in providing emotional support to the patients [10, 12, 17]; they also contribute to the physical aspects of patient care and assist the patients in activities of daily living [16–18]. Family members are included in discussions concerning patient care [13], and discussions regarding care plans should be conducted among the patient, family members and healthcare professionals [19, 20]. Participation in care varies depending on each family member [12, 15].

At home, family caregivers have a major role and a lot of responsibility for the patient's care [21, 22]. Also, their importance and role in the hospital environment have been acknowledged [13, 17, 18]. Previous reviews related to palliative care have synthesised knowledge concerning family caregiving in home-based palliative care [23, 24], patients' and their family members' experiences of palliative care in hospital [3] and important elements of end-of-life care [8]. No previous review was identified concerning family members' participation in hospital inpatient palliative care. Therefore, with this integrative review, we identified current research concerning family members' participation in inpatient palliative care to

increase existing knowledge on the topic and to guide future research.

AIM

The aim of this integrative review was to analyse how family members participate in hospital inpatient palliative care and how their participation could be supported. The ultimate goal is to increase current knowledge to be able to better support and encourage family members' participation.

METHODS

Integrative review design allows the inclusion of studies conducted using various methodologies. Studies conducted by various methodologies were included because the research on the topic is limited, and this also allows a comprehensive understanding of the research topic. This integrative review was performed following Whittemore and Knaf's [25] methodological approach, which includes five steps. First, we identified the problem. Second, a literature search in four international databases and study selection based on predefined inclusion and exclusion criteria (Table 2) were conducted. Third, the quality of the included studies was assessed using the Mixed Method Appraisal Tool (MMAT), Version 2018. Fourth, inductive content analysis was conducted, and fifth, the findings were presented.

Search

A literature search was conducted in March 2020 and updated in June 2021 on four electronic databases: PubMed (Medline), CINAHL (Ebsco), PsychINFO (Ebsco), and Cochrane Library. The electronic database search was also supplemented by a manual search, which was conducted by reviewing the reference lists of the included articles. The search terms used in the databases are described in Table 1, including palliative care, family member, participation and hospital. Also, database-specific MeSH terms, Boolean operators (AND, OR) and truncation of the terms were used. Term hospice was not included in the search since the aim of this review was on family members participation in hospital setting and for example studies concerning family members participation in hospice care facilities were not considered for this review. The authors assumed that by using terms "palliative care" and "terminally ill" with database-specific MeSH terms studies

TABLE 1 Search terms used in electronic databases

| Search terms | |
|-----------------|---|
| Palliative care | Palliative care, palliative patient, palliative nursing, terminally ill |
| Family member | Family, spouse, family member, relative, partner, wife, husband, loved one, next of kin, carer, caregiver |
| Participation | Participation, involvement, take part, attend |
| Hospital | Hospital, inpatient |

TABLE 2 Inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|--|---|
| Studies including a description of family members' participation in hospital inpatient palliative care | Studies conducted in intensive care units |
| Hospital setting | Studies focusing on palliative care of patients with dementia |
| Adult patients receiving palliative care in a hospital setting | |
| Adult family members | |
| English or Finnish language | |
| Peer-reviewed research articles | |
| Empirical studies | |
| No time limit was applied | |
| Suitable studies will be included for the review regardless of the critical appraisal results. | |

concerning hospice care would also be reached. For the literature search, assistance was received from information specialists at the Turku University Library.

Study selection

Empirical peer-reviewed articles including descriptions of family members' participation in the care of patients receiving palliative care in hospital inpatient settings were included in this review. The inclusion and exclusion criteria are described in Table 2. Studies conducted in intensive care units were excluded because critically ill patients are usually treated with life-sustaining treatment in these settings.

Altogether, 4988 articles through a database search and 2 articles through a manual search were identified. The screening of the articles was conducted in separate phases, as described in Figure 1. First, duplicates were removed, and then the remaining articles were screened for title and abstract. Subsequently, the remaining articles were screened for full text to assess the eligibility of the studies. The screening of the articles by title and abstract was undertaken by one author (JS) because of the large number of database search results, but unclear parts were discussed with other authors. The inclusion and exclusion criteria were clear and agreed together with other authors. The eligibility of the articles included for full-text review was assessed by two authors (JS and KM) and discussed together with all the authors.

Data evaluation

For the critical appraisal of the included studies, the MMAT (Version 2018) was used. This tool was chosen because the review includes qualitative, quantitative and mixed-methods studies. The MMAT includes two similar screening questions for each category, and then each category includes five criteria questions specific to each study design [26]. The quality appraisal of the articles was conducted independently by two authors (JS and KM), the results were discussed, and agreement was reached on each criterion.

The critical appraisal showed that the methodological quality of the included studies was good (Table 3). All the qualitative studies received a full score in the critical appraisal, but in the quantitative and mixed-methods studies, there were some discrepancies. No articles were excluded because of the results of critical appraisal.

Data analysis

Data were analysed using inductive content analysis, which can be performed for both qualitative and quantitative data [27]. Data analyses were conducted by one author (JS), and the results were discussed together with all the authors. The included articles were read through several times to get a clear overall picture of the data. The text was coded according to the aim of the review, and words, sentences and phrases (units of analysis) describing family

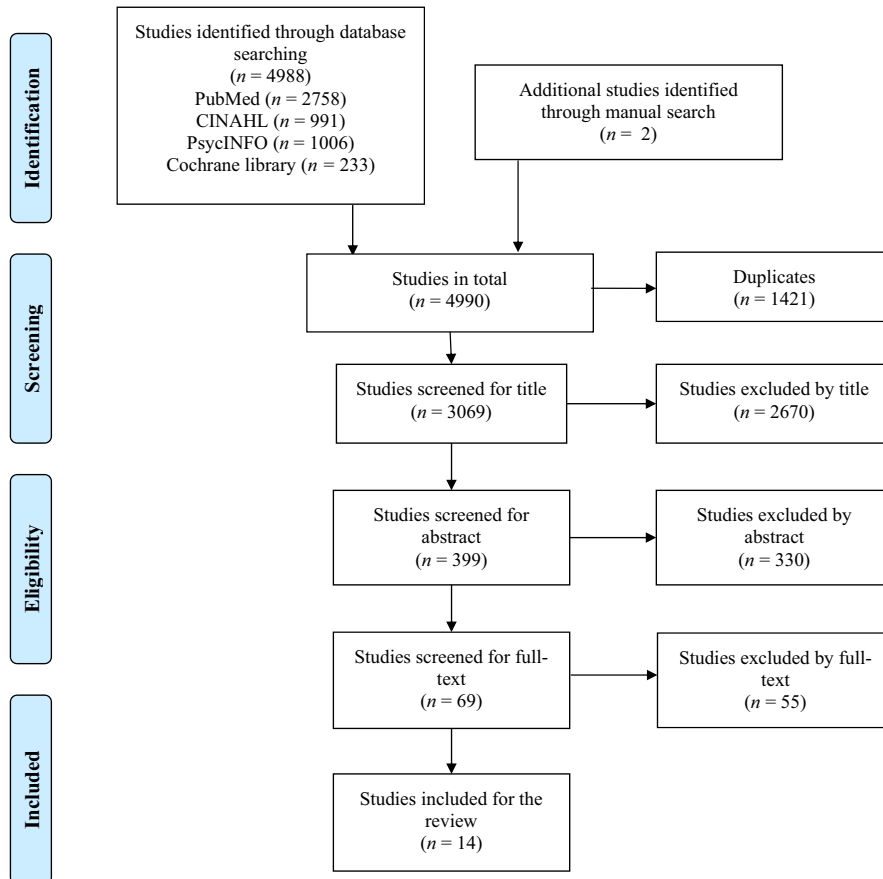


FIGURE 1 Flow chart of the search process, adapted from Prisma 2009 Flow Diagram [42]

members' participation in the care of patients receiving palliative care and the support provided to them were extracted. All the units of analysis identified from the data were gathered. First, similar content was combined into subcategories, and then main categories were formed.

RESULTS

Description of the data

Altogether, 14 studies were included in this integrative review (Table 4). These studies were published between 1985 and 2021. Five of the studies were published between 1985 and 2005 and the others between 2012 and 2021. Studies were conducted in nine different countries: Brazil ($n = 3$), Australia ($n = 3$), Finland ($n = 2$), the Netherlands ($n = 1$), New Zealand ($n = 1$), Norway ($n = 1$), Saudi Arabia ($n = 1$), the United States ($n = 1$) and Sweden ($n = 1$). Nine of the studies were conducted using qualitative methods, three using quantitative methods and two using mixed-methods methodology.

The studies were conducted in different settings (Table 4), including specialised palliative care units (units where the main task is to treat patients with palliative care needs) [28–32], oncology units [28], medical

units [28, 33], surgical ward [34], different hospital inpatient units [35–39] and acute settings [40, 41] such as acute units with palliative care beds (for example, oncology units with designated beds for patients receiving palliative care) [41]. The study population included healthcare professionals: nursing staff [28, 29, 31, 38, 39, 41], doctors [41], social workers [40], pastoral carers [41], family members [30, 33, 35], relatives [34, 37] and patients [36]. In one study, the data consisted of registration forms filled out by nursing staff [32]. Data collection in qualitative studies was mainly conducted by interviews, except in one of the studies, in which a questionnaire with open questions was used. Quantitative studies used mostly questionnaires for the data collection, and one of the studies used a registration form filled out by nurses. In mixed-methods studies, questionnaires, open questions and interviews were used.

Family members' participation in hospital inpatient palliative care

Data analysis resulted in four main categories describing family members' participation in inpatient care of patients receiving palliative care. These main categories include participation in the physical care of the patient, provision

TABLE 3 Critical appraisal of the studies

| Screening questions | | 1. Qualitative | | | | |
|---|--|--|--|--|---|---|
| SL. Are there clear research questions? | S2. Do the collected data allow to address the research questions? | 1.1. Is the qualitative approach appropriate to answer the research question? | 1.2. Are the qualitative data collection methods adequate to address the research question? | 1.3. Are the findings adequately derived from the data? | 1.4. Is the interpretation of results sufficiently substantiated by data? | 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? |
| Abudari et al. (2016) [28] | Yes | Yes | Yes | Yes | Yes | Yes |
| Andershed and Ternstedt (1998) [34] | Yes | Yes | Yes | Yes | Yes | Yes |
| da Cruz Matos and da Silva Borges (2018) [29] | Yes | Yes | Yes | Yes | Yes | Yes |
| Gott et al. (2019) [35] | Yes | Yes | Yes | Yes | Yes | Yes |
| Moon et al. (2020) [33] | Yes | Yes | Yes | Yes | Yes | Yes |
| da Silva et al. (2012) [30] | Yes | Yes | Yes | Yes | Yes | Yes |
| da Silva and da Silva Lima (2014) [31] | Yes | Yes | Yes | Yes | Yes | Yes |
| Virdun et al. (2020) [36] | Yes | Yes | Yes | Yes | Yes | Yes |
| Witkamp et al. (2016) [37] | Yes | Yes | Yes | Yes | Yes | Yes |
| Screening questions | | 2. Quantitative | | | | |
| SL. Are there clear research questions? | S2. Do the collected data allow to address the research questions? | 2.1. Is the sampling strategy relevant to address the research question? | 2.2. Is the sample representative of the target population? | 2.3. Are the measurements appropriate? | 2.4. Is the risk of nonresponse bias low? | 2.5. Is the statistical analysis appropriate to answer the research question? |
| Hadders et al. (2014) [32] | Yes | Yes | Yes | Yes | Can't tell | Yes |
| Kuuppelomäki (1993) [38] | Yes | Yes | Yes | Can't tell | Can't tell | Yes |
| Parry and Smith (1985) [40] | Yes | Yes | No | Can't tell | Yes | Yes |
| Screening questions | | 3. Mixed methods | | | | |
| SL. Are there clear research questions? | S2. Do the collected data allow to address the research questions? | 3.1. Is there an adequate rationale for using a mixed-methods design to address the research question? | 3.2. Are the different components of the study effectively integrated to answer the research question? | 3.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? | 3.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? | 3.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? |
| Kuuppelomäki (2003) [39] | Yes | Yes | Yes | Yes | Yes | Yes |
| Street et al. (2005) [41] | Yes | Can't tell | Yes | Yes | Yes | Yes |

TABLE 4 Included studies

| Authors, year, country | Aim | Participants, setting | Study design, method |
|---|--|---|---|
| Abudari et al. (2016) [28], Saudi Arabia | To study the experiences of non-Muslim nurses in caring for terminally ill Muslim patients and their families | Participants: Nurses ($n = 10$) from palliative care/oncology unit ($n = 5$), oncology units ($n = 3$) and medical units ($n = 2$) Setting: King Faisal Specialist Hospital and Research Centre, a tertiary care hospital and a regional cancer centre | Qualitative descriptive phenomenology design Semi-structured interviews |
| Andershed and Ternstedt (1998) [34], Sweden | To increase knowledge about relative's participation in the care of terminally ill cancer patients and to understand the relatives' sense of coherence | Participants: Relatives ($n = 6$) Setting: Different care cultures; surgical ward, nursing home, inpatient hospice ward and home care | Qualitative prospective study Interviews and informal conversations |
| da Cruz Matos and da Silva Borges (2018) [29], Brazil | To analyze the perceptions of nurses concerning family members' participation in palliative care | Participants: Nurses ($n = 10$) Setting: Palliative care ward, Brasília Support Hospital | Qualitative, exploratory, descriptive study Semi-structured interviews |
| Gott et al. (2019) [35], New Zealand | To identify from the perspective of family members' examples of good care provided at the end of life to older adults in hospital | Participants: Family members and whanau (extended family and friends) ($n = 21$) Setting: Relatives of the participants were treated in a public hospital | Qualitative study with a social constructionist framework Structured questionnaire, face-to-face, telephone and face-time interviews and field notes |
| Hadders et al. (2014) [32], Norway | To present the standardisation of relatives' participation at the time of death in the palliative medical unit and to explore the effects of the implementation | Data: Registration forms ($n = 400$) Setting: Palliative Medical Unit at Trondheim hospiersity Hospital | Descriptive study design A registration form filled out by nurses to describe the extent of relatives' participation at the time of death |
| Kuuppelomäki (1993) [38], Finland | To examine the ethical decision-making process to proceed to terminal care | Participants: Nurses ($n = 191$) Setting: Three healthcare units in health centre, central hospital and radiotherapy clinic | Quantitative study Mailed questionnaire |
| Kuuppelomäki (2003) [39], Finland | To describe provision of emotional support to terminally ill patients as assessed by nurses | Participants: Nurses ($n = 328$) Setting: Inpatient wards at community health centres | Questionnaire survey Structured questionnaire with open-ended questions |
| da Silva et al. (2012) [30], Brazil | To analyse nursing care provided to patients with advanced cancer during hospitalisation from the perspective of family members and to analyse their participation in the care | Participants: Relatives ($n = 8$) Setting: Unit specialised in palliative oncology care, Hospital do Cancer IV | Exploratory study with qualitative approach. Methodological framework of grounded theory was used Semi-structured interviews |
| da Silva and da Silva Lima (2014) [31], Brazil | To understand family members' participation in palliative cancer care from nurses' perspective and to identify nursing care strategies to attend to their needs | Participants: Nurses ($n = 17$) Setting: Specialised palliative care unit, Hospital do Cancer IV | Descriptive study with a qualitative approach Semi-structured interviews |
| Moon et al. (2021) [33], Australia | To examine the experiences of bereaved family members on end-of-life decision-making in medical units | Participants: Bereaved family members of patients who had received end-of-life care ($n = 28$) Setting: General medicine units of one large public hospital in Melbourne, Australia | A qualitative exploratory study with a social constructionist epistemology Semi-structured interview |

TABLE 4 (Continued)

| Authors, year, country | Aim | Participants, setting | Study design, method |
|---|---|---|--|
| Parry and Smith (1985) [40], USA | To investigate social workers' perspectives towards the patient and family as a unit of care in relation to terminally ill patients | Participants: Social workers ($n = 100$) Settings: General acute hospitals, hospices and skilled nursing facilities | Quantitative study Structured interviews |
| Street et al. (2005) [41], Australia | To examine the management of family-centred palliative care in different aged care and acute care settings | Participants: Healthcare professionals (nurses, doctors, pastoral carers and others). Interviews ($n = 90$), questionnaire ($n = 425$) Setting: Hospitals with palliative care units and community-based hospice units, aged care units, residential aged care facilities and palliative beds in acute units | Mixed-methods study Semi-structured interviews and a questionnaire |
| Virdun et al. (2020) [36], Australia | To identify the perspectives of patients with palliative care needs about their recent hospitalisation to determine the relevance of domains noted internationally to be important for optimal inpatient palliative care and how these can be operationalised | Participants: Adult patients with palliative care needs ($n = 21$) Setting: Hospitals ($n = 5$, 4 metropolitan, 1 remote) | An exploratory qualitative study, the philosophical worldview of pragmatism was used Semi-structured interviews |
| Witkamp et al. (2016) [37], Netherlands | To identify relatives' experiences of their involvement in the hospital during the patient's end-of-life care | Participants: Relatives ($n = 451$) Setting: Erasmus University Medical Center | Retrospective questionnaire study with qualitative approach Questionnaire with closed- and open-ended questions (Open-ended questions analysed in this article) |

TABLE 5 Family members' participation in hospital inpatient palliative care

| Family members' participation in hospital inpatient palliative care | | | |
|---|---|--|--|
| Participation in the physical care of the patient | Provision of emotional support to the patient | Promoting good patient care | Support provided by healthcare professionals for family members' participation |
| Assisting patient in daily activities | Visiting the patient in the hospital | Participation in decision-making related to patient care | Active communication and adequate information |
| Participation in post-mortem care | Being with the patient in the hospital | Acting as a patient advocate in the care | Guidance for participation |
| Participation offering assistance to nurses and learning opportunities for family members | | | Supportive hospital environment |

of emotional support to the patient, promoting good patient care and support provided by healthcare professionals for family members' participation (Table 5).

Participation in the physical care of the patient

Participation in the physical care of the patient consists of three subcategories: assisting patient in daily

activities, participation in post-mortem care and participation offering assistance to nurses and learning opportunities for family members. Family members participated in the physical care of the patient while visiting the hospital [28, 30, 31, 34, 41]. Assisting the patient with daily activities [30] included assistance in ambulation [30], hygiene [30, 31, 34, 40], toileting [40], eating and feeding [30, 34], making the bed [34, 40] and positioning the patient [30]. Family members also assisted the patients by taking them to examination [35]. Giving

medication was not usually allowed for family members in hospitals [40].

Family members' participation has been acknowledged at the moment of death, and they participated in post-mortem care [32, 41]. Family members were allowed to participate as per their own wishes; they could, for example, comb the hair of the patient and assist with washing and dressing the body. Participation in post-mortem care depended on the willingness of the family members, and they could just choose to be present in the situation [32].

Family members' participation offered assistance to nurses [30, 31], and they were active part of the care team [29, 31]. Nurses could ask for help from family members [30] and teach them different skills [30, 31]. One major benefit of it is to prepare them for discharge. Participation in the hospital offers an opportunity to learn skills that they will need when possibly transferring to home care in the future [30, 31].

Provision of emotional support to the patient

Provision of emotional support to the patient consists of two subcategories: visiting the patient in the hospital and being with the patient in the hospital. Family members play an important role in the emotional support of patients receiving palliative care [28, 30, 31, 38]. In the study of Kuuppelomäki [39], the results show that terminal care patients mostly receive emotional support from nursing staff and family members, but other relatives and friends also offer emotional support to the patient.

Family members often visited the patient in the hospital, and they spent time together [34, 35]. Sometimes, family members even spent the whole day with the patient [34] and wished to stay for the night [35]. Visiting the patient in the hospital provided an opportunity for the family members to show their feelings [37]; it provided an opportunity for the family members and patients to have discussions or just sit next to each other [32, 34]. In the study of Abudari et al. [28], it was also witnessed that family members took care of the spiritual needs of the patient.

Being with the patient describes family members presence in the hospital. The presence of family members in the hospital is considered important by healthcare professionals [28, 30, 39] and family members [31, 35]. They support the patient as the disease progresses and when death is approaching [29]. The presence of family members is considered to support the well-being of the patient [37], provide comfort [29, 30, 36] and increase feelings of

safety [29, 30]. Family members were also present at the bedside at the moment of death [32, 34, 37].

Promoting good patient care

Promoting good patient care consists of two subcategories: participation in decision-making related to patient care and acting as a patient advocate in the care. Family members were involved in decision-making related to patient care [28, 33, 35, 37, 38], including discussions related to patient care during hospitalisation [28, 35, 37] and discussions related to end-of-life care [33, 38]. Family members participated in the decision-making together with the patient and healthcare professionals or alone with healthcare professionals [33, 37, 38] in situations where the patient is incapable of participating [33, 37].

Family members' roles in decision-making related to patient care varied. In the study by Kuuppelomäki [38] considering decision-making regarding starting terminal care, family members were not always considered in the decision-making process, and it was common for healthcare professionals to make the decisions [38]. This was also noted in the study of Moon et al. [33], but some family members also experienced that decision was left for them to process. Family members who spent more time next to the patient in the hospital experienced more often that they had a chance to participate; in other cases, it was difficult to get a chance to talk with a doctor about the situation of the patient [37]. In the study of Abudari et al. [28], nurses also described that family members took an active role in the decision-making concerning patient care, and the role of the patient was almost absent. This was experienced as hurting patients' autonomy although the purpose of family members was to protect the patients. This was considered culture related.

Acting as a patient advocate in the care is a role that family members can adapt while the patient is being treated in the hospital [37], and it has been experienced as important by family members [33]. Acting as a patient advocate can be related to decision-making; they provided support to the patient in discussions related to the care and emphasised the patient's preferences [33]. Family members know the patient best, and they have information related to patient care that they can share with healthcare professionals [29, 33, 37]. When family members stayed with the patient in the hospital, nurses could ask them about the patient's condition, such as nutrition, evacuation and possible concerns [31].

Family members also took responsibility in the patient care; it was important for family members to make sure that the patient was well taken care of [34]. In the study of Andershed and Ternstedt [34], some of the family

members experienced a major role in the care; it was experienced that the nursing staff were more task-oriented and did not pay enough attention for them and the patient. In the study of Witkamp et al. [37], some family members experienced care as inadequate; for example, they experienced that the patient was not assisted with feeding if they were not around. The abovementioned situations caused stress in the family members.

Support provided by healthcare professionals for family members' participation

Support provided by healthcare professionals for family members' participation consists of three subcategories: active communication and adequate information, guidance for participation and supportive hospital environment. Studies emphasised active communication concerning patient condition and the situation as part of patient care [30–32, 34, 37]. Adequate information concerning patient care was important for family members. This allowed them to participate in decision-making concerning patient care [33, 37]. Information provided to family members about the changes in patients' condition over time allows family members to be present at the moment of death [32]. In the study of Gott et al. [35], family members experienced that the information they received was adequate, and they were satisfied with the professional's way of taking them and the patient into consideration during hospitalisation. Instead, in the study of Andershed and Ternstedt [34], family members experienced that the information during hospitalisation was inadequate.

The studies identified different aspects that could offer guidance for family members' participation. Participation could be supported by identifying tasks that are suitable for them and which they are willing to take part in Ref. [41]. Different ways to guide family members' participation in care could include showing examples [31, 35], teaching [30], assisting in patient care [41], multidisciplinary teamwork [30], information leaflets [31, 35] and support groups of family members [31]. Family members' participation during the time of death can be enabled by informing them regarding changes in the condition and by talking with them about the ways they want to participate [32].

A supportive hospital environment encourages family members' participation. Family members provide support to the patient, and therefore their participation should be accommodated [39]. It has been considered important for family members to have the opportunity to visit any time of the day and spend the night next to the patient [37] and the possibility for a single room to have a private and

quiet environment [35]. In the study of Andershed and Ternstedt [34], it was experienced that the hospital environment allowed their participation, and there was an opportunity to visit all day.

DISCUSSION

The aim of this integrative review was to analyse how family members participate in palliative inpatient care, and how their participation could be supported. Participation has been experienced as important by family members [30, 34], patients [36] and healthcare professionals [31]. Family members' participation varies, and they participate in different aspects of care. Family members assist the patient and nurses with the physical aspect of care; they support the patient emotionally and have a role in promoting good patient care. This participation can be supported in different ways, including active communication and providing information related to patient care.

Family members' participation in inpatient palliative care has been studied from different perspectives, in different settings and with different methods. Although the first study included for this review was published in 1985 and family members' participation has been identified as important in previous studies [8], the studies conducted in the hospital setting are still rare. Only a few studies examined the overall participation of family members in hospital inpatient care. Some of the studies focused on certain aspects of care, including decision-making, emotional support and participation at the moment of death. There were only five studies conducted from family members perspective and one study from patients' perspective, which might be because the studies concerning the topic are still rare and also because of the vulnerability of patients and their family members in this situation. The studies were conducted in different countries and continents, but there were no studies conducted in parts of Asia or Africa, which might be because of the development of palliative care and the fact that only studies published in English or Finnish were considered for this review.

Participation of family members allows them to assist and help the patient [30, 34]. Family members' presence was preferred by nurses even though it would also increase their workload [31]. The included studies showed that the family members' participation in the physical aspect of care varied and was either initiated by the family members themselves or by the request and under the guidance of nursing personnel. One goal of family members' education regarding care activities was to prepare them for discharge [30, 31]. This is important to consider in clinical settings because patients often wish to be cared for at home, where family members assist them with the

physical aspect of care. The care provided by family members in hospital settings is similar with the tasks they do at home, but at home, family members often take care of the multiple care needs of the patient all day around [21]. This is different in hospital settings, where health care professionals take the responsibility on the care and family members might even feel shy to participate if they are not provided with information and guidance to support their participation. Hospitals may be unfamiliar environments for family members, so it is important for them that their role is acknowledged by healthcare professionals because this also facilitates participation [37].

Family members' role in providing emotional support was emphasised in the studies included in this review; it is an important aspect of palliative care [39]. Patients' situation in palliative care affects their emotional well-being, and they might feel lonely in a hospital environment. Visiting and supporting the patient is something that is natural for family members and should be encouraged by healthcare professionals [10].

Family members' participation in decision-making was described only in a few studies [28, 33, 37, 38]. This might be because there are no situations for family members to participate; the decisions are made by healthcare professionals based on patients' clinical condition or communicated only with the patient. In the study of Moon et al. [33], family members' active role as a patient advocate was highlighted in the decision-making process. This role was also related to patient care, and according to the findings, this role was important for family members, who wanted to improve the quality of life for the patient and ensure that good care was provided [33, 34, 37]. It has been noted in a previous study by Belanger et al. [12] that when family members experience being involved in patient care, it might also support their coping process. Different aspects of palliative care should be communicated with patients and their family members if it is something that they both wish for.

Family members' participation affects the physical and emotional well-being of the patient and might affect the length of hospital stay [30]. Family members' participation can be supported in different ways. In this review, active communication and adequate information were emphasised to allow family members' participation. These findings are similar to those of the previous studies related to hospital inpatient care [11, 12]. In the study of Andershed and Ternsted [34], family members experienced that there were no care activities that would aim to increase their participation. In the study of Hadders et al. [32], it was reported that the registration form developed and used in the study also supported nurses in noticing the family members' role in the dying phase. Different methods guiding family members in their participation

described in this review could easily be used in clinical settings. Healthcare professionals in clinical settings should take the family members of the patient into consideration in the hospital environment to support them in participation and acknowledge their role in patient care. There should be enough resources and specific guidelines to support this. As also concluded in the study of Tarberg et al. [22], family members' participation in palliative care should be considered in nursing education.

CONCLUSION

Family members' participation in hospital inpatient palliative care consists of participation in different aspects of patient care, concerning physical, emotional and practical care and also decision-making. This participation depends on the needs of the patient, varies between each family member and is affected by the hospital environment and the way healthcare professionals acknowledge their role. Participation offers support to the patient, promotes good patient care and could also enhance the coping of patients and family members at home. Active participation in the care is a way for family members to offer their support and to ensure that the patient receives good care and that their needs are being met. Healthcare professionals in clinical settings should support family members' participation in different ways and also educate them about the possibilities to participate.

Research concerning family members' participation in hospital inpatient care is still scarce. Less than half of the included studies examined family members' and patients' experiences; therefore, future research is still needed from different perspectives concerning different aspects of care. Also, intervention research is needed concerning support provided for family members' participation.

STRENGTHS AND LIMITATIONS

The literature search was conducted in four electronic databases considered relevant for this topic and supplemented by a manual search with the goal of identifying the relevant studies. There are also factors to be considered in the review process. For the literature search, assistance was received from information specialists. There is a possibility that some relevant studies might have been missed because only peer-reviewed research articles were included, the language of the studies was limited to English and Finnish and only one author conducted the review of the studies by title and abstract. To strengthen the review process, the inclusion and exclusion of the studies were discussed with all the authors when necessary. Studies concerning

patients with dementia and studies conducted in intensive care units were excluded from this review. This might affect the results of this review, as some information might have been missed, but it was considered that family members' participation in these settings would include special aspects. Data were analysed by one author, and the results and categories were discussed together with all the authors to support the trustworthiness of this review.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTIONS

Study design (JS, KM, EH), data collection (JS, KM, EH), critical appraisal (JS, KM), data analysis (JS, KM, ASJ, EH) and writing of the manuscript (JS, KM, ASJ, EH).

ETHICAL APPROVAL

No formal ethical approval was required for this review.

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