REVIEWS

The invisibility of the patient's family in nursing documentation: An integrative review

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ABSTRACT

Objective: The objective of this integrative review is to present the current state of research knowledge regarding references to the patient's family in documentation in health care settings.

Methods: Ten (N = 10) research articles from 1998 to 2014 were found and analyzed using inductive, thematic analysis. All articles were evaluated using the critical appraisal tools developed by the Joanna Briggs Institute (JBI).

Results: Two main themes were revealed: the content and the structural aspects of family documentation. Quantitative, qualitative and mixed methods were used in generating the data of the reviewed articles. Reference to families in documentation was considered important in all the articles. Structural aspects consisted of semi-structured forms, summary notes and a tick-box system for marking the issues which were discussed with families. The classification system and outcomes assessment regarding family documentation were investigated, and their importance was highlighted. The content of family documentation was typified, for example, by parenting issues in mental health status and how the parents cope when a child is ill. Difficult life situations and advanced care planning brought families into the documentation, albeit rather infrequently. Similarly, references to counseling families or considering their psychosocial, spiritual and cultural dimensions were rarely found in the literature. Additionally, the family's importance in supporting the patient's care was often missed in documentation.

Conclusions: The results show the necessity of developing both family nursing and its documentation. Consequently, in order to improve the quality of both of these, more investigation from multiple perspectives is needed.

Key Words: Patient's family, Family nursing, Nursing documentation, Family documentation, Patient records, Integrative literature review

1. INTRODUCTION

The aim of family nursing is to help both patients and families maintain a supportive relationship in health care.[1,2] The focus of family nursing is on both the patient's and the family members' concerns in various health/illness situations.[2,3] It is also important to understand that family nursing includes the entirety of a person's lifespan, thus applying to patients from child care to elderly care in all health care settings.[3]

The important goal in all its phases is to promote the well-being of the whole family.[3] In this integrative literature review, the focus is on revealing how the presence of the patient's family is documented in patient records.

The importance of collaboration between hospital staff and patients' family members has been studied widely.[4–7] The bond between family members is fundamental. When patients are in hospital, they are still members of their fam-

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ily. Patients worry about their family members, and vice versa.[8] Being separated from family members can lead to distress as well as physical and psychological disorders.[9] The importance of family presence and visitation is also much appreciated in acute critical situations.[10, 11] Smith et al.[12] indicated that open and flexible visiting times in intensive care units increased both patients' and family members' satisfaction, leading to positive changes for all the family. Moreover, it is important that adult patients themselves define their close family members[10] and make the decisions regarding family members' participation in their care.[13] Family members are often the patients' legal representatives and thus act as advocates for the patients in difficult health situations.[14] Furthermore, both patients and family members need informational and emotional support in order to cope at home.[15] In a study by Mattila et al.,[15] the nurses supported patients and families, e.g., by caring, giving information, and dealing with emotional situations. By having a supportive relationship with the nurses, the family members felt accepted and available to be involved with their close one's treatment. However, when the support was inadequate, the family members felt themselves "outsiders" regarding the treatment given their close ones.[15] Sharing information with the family members gives them an understanding of how they can cope in the at-home collaboration.[16] Nevertheless, according to Majasaari et al.,[17] the patient's family members seem to be quite invisible, e.g., in discharge counseling situations.

Genuine patient-focused documentation reveals the voice of the patients[18] and, as an integral part of nursing, documentation has a crucial place from the family perspective as well.[8, 18, 19] Browning[20] stresses the importance of family documentation, which may be advanced by electronic records; documentation is a beneficial way to collect data from family members for interdisciplinary collaboration.

Documentation of relevant information in patient records is a legal responsibility worldwide. Writing patient records concerns all health care professionals.[21] There are occasions in health care when authorized family members have to take responsibility for making decisions on behalf of the patients, e.g., because of the patient's health condition. In situations when patients cannot communicate, there are significant family issues which need to be documented.[10] When family members take responsibility for the patient's care, the documented information is essential.[22] For example, in the country of the present authors, Finland, the status of close relatives or legal representatives as patients' advocates is spelled out in the law.[23]

Current health systems are complex.[8, 24] In the totality of one care process, patients can be treated in numerous units

with multiple health professionals participating.[24] In such fragmented and complex situations, an effort needs to be made to involve family members in the patient care.[24] To support the continuity, effective documentation is required[8, 25, 26] and it is a way to both communicate with the interdisciplinary professionals[20] and promote the patients' safety.[27]

Patients themselves appreciate when nurses involve their family members in their care.[19, 28] It has been shown that it was often the patients' own initiative in establishing that their spouse could come to an admission meeting with a nurse or to a doctor's appointment. This was a way to have emotional and informational support.[8] Family members' participation in the patient's life can be crucial in the time ahead,[2, 7, 29] as they are the ones who primarily take care of the patients at home after discharge; hence, they need guidance and support from competent professionals.[11, 28, 29] When patients and their family members live their lives outside of hospitals, but using health care services, the continuity of high-quality treatment can be ascertained by means of accurate documentation.[8] Such documentation is also needed when family members are the permanent caregivers of their loved ones, in order to support all the parties in coping.[29–32]

In several previous studies concerning documentation, the importance of family members has been mentioned.[33–35] Also, families' participation was documented in regard to coordinating the continuity of care.[18] However, the actual participation of family members in the patient care is, in general, quite briefly noted in such documentation, even though it has a crucial relevance for the patient's discharge from hospital and survival at home.[36] As part of their action research, Okaisu et al.[37] included the family nursing perspective in the hospital admission process in order to improve the documentation. So, the importance of patients' family members has been noticed as participants in the treatment, but their visibility in documentation has remained on the level of mentioning.

Nursing documentation has been extensively studied and many literature reviews have promoted a vast body of knowledge from multiple viewpoints.[34, 38–43] However, the interest of the authors of this paper has been piqued by the apparent absence of any previous literature review specifically focusing on family documentation. Therefore, the aim of the authors here is to conduct an integrative literature review of the existing knowledge on this topic.

Purpose of the study

This integrative literature review aims to describe existing research knowledge regarding documentation which has been

done concerning the family while one of them is a client or patient in some health care setting.

The research question is: What is known about family documentation in health care settings?

2. METHODS

This study is based on an integrative review method which includes problem identification, a literature search, data evaluation, data analysis and reporting the results.[44] The integrative review method is very suitable for synthesizing data available in topics which have scarcely been studied, such as family documentation. Studies included in an integrative review can be done by different research methods and the results are presented in narrative form, often by thematic analysis. This approach facilitates the acquisition of a detailed general understanding of a research focus. This understanding can generate additional studies or development in the area.[45]

2.1 Database search and selection of articles

Data searches were performed with assistance from an information specialist at the University of Tampere library. The search terms were carefully selected by the researchers and the information specialist and the searches were planned and conducted together in the databases Cinahl and Medline. The search terms are described in Figure 1. The terms were used in all possible combinations, for enhancing finding of all studies which answer our research question. A manual search was also conducted in reference lists of articles already selected for the review. Figure 1 describes the search, search terms and selection processes of the data for this study. Data search and selection were quite complex, due to the lack of studies concerning the topic, i.e., family documentation. Many studies first showed promising but after reading them, they were not about the topic of interest. Excluded articles did not meet the inclusion criteria and are not presented.

Data of the included articles were analyzed and described in Table 1. The table consists of the authors of the article, country, critical appraisal; aims; methods and participants of the study; and the results related to family documentation, reduced from the original studies selected in this integrative review. Data included only original articles or those which were part of a larger study but reported as an individual study. The articles were published in Japan (n = 1), Canada (n = 2), Australia (n = 2), Sweden (n = 1), the USA (n = 2), Norway (n = 1) and the Netherlands (n = 1). Mixed-method studies (n = 2) used both a quantitative and qualitative approach. The research data (N = 10 studies) also include studies using only qualitative (n = 5) or quantitative (n = 3) approaches. Research concerning family documentation was

done in the contexts of patient education, health promotion, chronic illness, palliative care and mental health, concerning both children and adults.

2.2 Data evaluation

All selected articles were critically appraised using the criteria presented by the Joanna Briggs Institute (JBI). Separate assessment criteria are outlined for qualitative, quantitative and mixed-method studies.[46] Each assessment tool has up to 11 criteria statements which were then evaluated. The quality of articles was acceptable, varying from 4 to 10 points; the points of each study are described in more detail in Table 1. However, they were the best which were available for this little-studied topic.

2.3 Data analysis

Thematic analysis[47] allows recognition of significant topics or prominent themes, as well as organized and structured ways of dealing with the content under these themes. It also allows integrating the data from qualitative and quantitative studies, while summarizing the results of different studies under thematic headings, based on the data. Thematic, inductive data analysis was conducted to reveal the themes among the review articles, based on the research question. In order to identify the themes, the chosen articles were read multiple times.[44, 45, 47, 48] Text segments answering the research question were first reduced in Table 1 and after that named and combined, according to their content. Two main themes were revealed, describing the content and structural aspects of the family documentation.
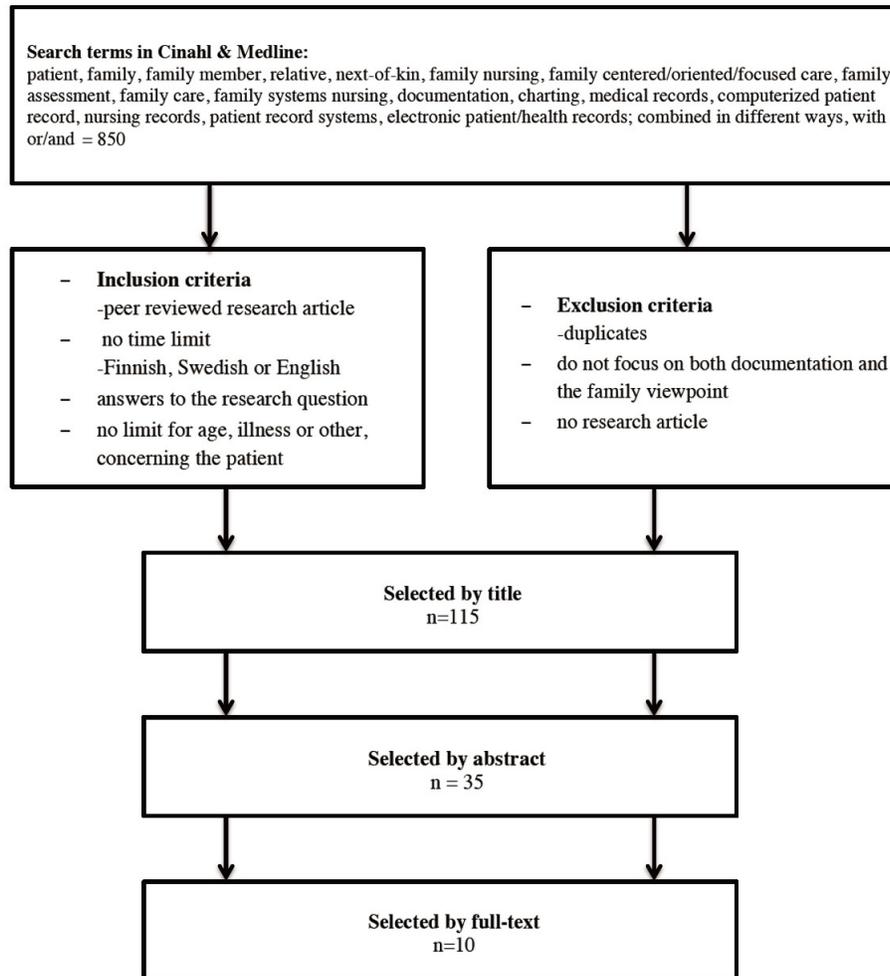
3. RESULTS

In general, documenting different aspects of families, besides the patient, was considered important in all papers included in this study. Two main themes are presented in the following.

3.1 Structural aspects of family documentation

Family care was considered as one central domain of documentation.[49] Family relationships, describing key persons in patient care, are crucial.[50] It is important that the documenting system requires who in the family should be included in the care of the patient.[51]

Nurses' notes, both in a semi-structured format and as summary notes, are essential for describing high-level family-centered work.[51] Also, the use of tick boxes, while discussing important points of care with families, is essential.[52] A classification system in documentation is needed for structuring the documented issues in a format which advances their use as the basis of care. Quality indicators[49] and describing care outcomes concerning families[53] are means for

the assessment of care. Heimendigger's study[53] contained various measures, thus the findings from the documentation were not directly within reach. However, the study gives a worthy pattern for the use of documentation, including a standardized methodology for how issues are discussed with a patient's family members and how they are documented.

Search terms in Cinahl & Medline:
patient, family, family member, relative, next-of-kin, family nursing, family centered/oriented/focused care, family assessment, family care, family systems nursing, documentation, charting, medical records, computerized patient record, nursing records, patient record systems, electronic patient/health records; combined in different ways, with or/and = 850

– **Inclusion criteria**
  -peer reviewed research article
– no time limit
  -Finnish, Swedish or English
– answers to the research question
– no limit for age, illness or other, concerning the patient

– **Exclusion criteria**
  -duplicates
– do not focus on both documentation and the family viewpoint
– no research article

Selected by title
n=115

Selected by abstract
n = 35

Selected by full-text
n=10

Figure 1. Database searches and data selection, by inclusion and exclusion

3.2 Content of family documentation

Parenting issues comprise an important aspect of the work of community mental health nurses, and there is a need to highlight the systematic identification of parental status in mental health patients.[54] Documenting parenting issues is considered important, e.g., parents expressing difficulties in coping with their role in the context where their child is ill.[54] Miyashita et al.[49] found that expectations of the family in discussing crucial issues, e.g., about do-not-resuscitate, are very important to document. Similarly, Heyland et al.[55] emphasized the importance of documenting advanced care planning for end-of-life care. However, even though patients and family members expressed preferences when asked about end-of-life care, in almost 30% of the included data their views were not documented.[55]

Family presence during counseling,[50] family-focused nursing diagnoses[56] and psychosocial, spiritual and cultural aspects of patient and family care[57] were found to be important to document, however infrequently this is actually done. It was found that family members are a supportive resource in care; however, this is not as well documented as it should be.[56] Heimendigger[53] found it important to document family visits and coaching conversations with them. Family advisors documented the time, date, and location of the visit, as well as family member participation, personal involvement and family dynamics during those conversations.[53]

According to Rotegård,[58] the family was mentioned in documentation from motivational and protective perspectives of how the patient felt about the family, and especially concerning (1) the patient's children, e.g., the wish to see them

grow, and (2) the spouse, in regard to issues such as worry and exhaustion. Thus, it was an important aspect to describe the patients' feelings about their family members.

The involvement of families in documentation of the education provided at patient discharge was investigated by Cook et al.[50] In the electronic medical records of patient education documented most often (n = 173), the frequency of patient and family together was 23, while the frequency involving the family alone was quite low (n = 3).

This literature review showed discrepancies between nursing care and its documentation. Hegarty et al.[57] noted that the families' concerns were part of the nursing care, but these concerns only rarely showed up in the documentation. According to Heyland et al.,[55] the preferences which patients and families expressed were not consistent with what was written in the documentation.

In the study by Ziegert,[56] the revealed themes emphasized the family members' supportive resources, enabling their readiness to contribute to the patients' home care and to co-operate with them in that care.

4. DISCUSSION

4.1 Discussion of the results

It is important to emphasize that the present authors' focus was especially on family nursing documentation. While, in general, patient documentation has been thoroughly investigated, curiously, family documentation[18] has not. However, there are many studies[18,59] which stress the need for family documentation and have contributed to the development of family documentation.

With the exception of the study by Ziegert et al.,[56] there were no other studies concentrating purely on family documentation. Documentation was used as a data collection method, among others, in several studies. Myashita et al.[49] used medical charts to find quality indicators of cancer patients' end-of-life. Heimendinger et al.[53] assessed the outcomes of a coaching program, with the purpose of promoting a healthy lifestyle among schoolchildren. Rotegård et al.[58] investigated the health assets of cancer patients.

When a patient falls ill, the significance of the family is crucial. On the basis of the results revealed in the present study, the importance of family involvement in documentation should be strongly emphasized. However, the results of this integrative review, as well as of other previous studies, found that the families in fact seem to be invisible in the documentation. This was confirmed in the literature review performed by Saranto and Kinnunen.[34] The family members' presence was often noted in documentation, at some level, but they were objectified. This is consistent with the results of a study by Laitinen et al.[26]

Furthermore, Reeves et al.[60] observed that even though family members are ordinarily present in the ICU, their day-to-day interactions with the interprofessional care team have not been explored or documented. Documenting central issues concerning the family, besides the patient, is crucial for teamwork enhancing high-quality care. It is important to understand that professional competence is not only knowledge and skills in a specialized clinical area. The competence needs to be shown in the skills of interaction or communication with the patients and interdisciplinary partners.[8]

Studies included in this review describe family documentation as part of the diverse information retrieval. Personal experience as well as beliefs, attitudes and mindset are reflected in the writing.[61,62] There is an old saying "if it is not documented, it is not done". This may reflect the fact that some health care professionals are more task-oriented than patient- or family-oriented. If health care professionals and, even more, the organizational hierarchies are not accountable for their patients' and family members' well-being and related documentation in the first instance, then a huge amount of valuable information for the continuity of care is lacking.[8] The complexity and fragmentation of health care are acknowledged in previous literature.[8,11] Consequently, without serious concentration on family members' involvement in nursing documentation, the safety and quality of the care processes are diminished. By taking action towards both family nursing practice and related documentation, the continuity of care would be improved.

4.2 Ethics and the reliability of the study

The authors of this paper have followed the guidelines of research ethics.[63] Since this is an integrative review, the focus has been on transparency in the study process.[44] The two authors both conducted the literature review. The data search was carried out first in collaboration with an information specialist at the university library. A wide range of key words and search terms was used in various search engines. The authors decided to use only English language terms, after noticing that their native language, Finnish, did not give any results in regard to the research question. Also, a hand-search was performed, which yielded one more article. This can be considered as enhancing the reliability of the data search, since the total number of research papers about the topic remained small. All the stages of the review were conducted in agreed collaboration by both authors. This review is therefore limited to the surprisingly small number of studies pertaining to the review question. Significantly, of the included articles only one was purely focusing on family nursing documentation.[56] However, this can be considered as a result, giving a wide-open field for further investigations.

Table 1. The studies included in the integrative review

Author(s), year, country, critical appraisal result	Aims	Methods and participants	Results describing family documentation
Ziegert K, et al.[56] 2007, Sweden 8/10	To examine the professional support for the next of kin (NoK) of chronic haemodialysis patients, as documented in the patient records.	• Total of fifty (N = 50) patient records, each approximately 100 pages. VIPS-model was the organization of the records. • Content analysis	• family's role should be documented in family-focused nursing diagnoses • family members are a supportive resource in the nursing care
Cook L, et al.[50] 2008, USA 4/9	To assess the frequency and nature of documentation of patient education by interdisciplinary staff in electronic medical records.	• Review of electronic medical records of discharged inpatients (N = 244). • Teaching intervention • Quantitative analysis	• most electronic patient records lack any patient education • if documented, was done by nurses • also some family presence during education was documented • the system requires who in the family should be included in the educational process
Feeley N, et al.[51] 1998, Canada 6/10	To describe the development of three classification systems health concerns of the families, strategies to attain the goals and the observed outcomes.	• Intervention • Recruited and consented families (N = 332) randomly selected families with chronically ill child, assigned to intervention group (n = 171) or control group (n = 161) • Content analysis	• documentation should be done about the actions the nurses take to help families achieve their goals • nurses' notes (semi-structured format): description of the family's current situation, the nurse's assessment, strategies for intervention, any outcomes or changes noted • summary note: brief summary of the major features of the work with each family
Hegarty M, et al.[57] 2005, Australia 9/10	To explore divergences between nurses' knowledge and their documentation in palliative care.	• Retrospective case-notes of deceased patients (n = 20) • interviews of the nurses who were involved with patients' care • Qualitative interviews • Quantitative audit	• psychosocial, spiritual and cultural aspects of care are infrequently documented
Heimendinger J, et al. [53] 2007, USA 7/10	To assess the outcomes of a coaching programme, aiming to promote healthy diets and physical activities among school children.	• Eighty-eight (N = 88) recruited families were randomly chosen to an intervention group and a 'delayed-control conditions'. • Statistical analysis • Qualitative interviews • Chart review.	• documenting the visits, coaching conversations • family advisors documented time, date, location of the visit, family member attendance, individual degree of involvement, and family dynamics
Van Loo M, et al.[52] 2008, UK 7/10	To assess the frequency of initiation and non-initiation of discussion about tissue donation with suddenly bereaved relatives, by emergency nurses.	• Patients' computerized case notes (n = 242) • Statistical analysis	• nurses recorded notes on the computer, using a tick box when they discussed tissue donation with the relatives • the initiation episodes by individual nurses occurred occasionally from one episode to eight; the non-initiation episodes occurred from one to eighteen
Rotegård A, et al.[58] 2012, Norway 7/10	To describe health assets based on analysis of nursing documentation in cancer patients' records.	• Content analysis	• family was mentioned in documentation regarding relational, motivational, and protective perspectives concerning how the patient felt about the family • were connected with children (wish to see them grow, says that they handle the illness well), and spouse (is worried about her/him, sees that the spouse is exhausted)
Heyland DK, et al.[55] 2013, Canada 6/9	To determine the prevalence of an advanced care plan and its components, from the perspectives of acutely ill patients and their family members, To determine the concordance between the patients' wishes and the care plan documented in the medical record. To assess the patients' and family members' overall satisfaction with end of life communication and decision making during the last four weeks.	• 278/513 patients (54.2%) • 225/366 family members (61.5%) in 12 acute care hospitals • Interviews with patients and family members using a questionnaire; • The medical record review immediately after the interview	• less than a third of the patients and families were asked about the advanced care plans (ACP) • patients' preferences about end of life care were poorly documented and there were discrepancies between the preferences and their documentation; family members have expressed preferences for medical treatments at the EOL • communication with health care professionals and documentation of EOL care preferences is inadequate
Liangas G, et al.[54] 2014, Australia 6/10	To audit parental records about the issues of parental concerns regarding their children's mental health issues.	• Audited files (N = 280), • 175 (n = 175) with parental concerns training intervention • Quantitative analysis	• parenting issues are a significant part of the work load for mental health teams • need to highlight systematic recognition of parental status involving mental health patients • parenting issues documented: parents expressing difficulties in coping with parental role, parents rely on children for support, parenting support, children's welfare and safety, parenting issue mentioned as a problem
Miyashita M, et al.[49] 2008, Japan 9/10	To identify quality indicators (QI) of end-of-life of cancer care by reviewing medical charts.	• Modified Delphi method, based on systematic literature review about QI using communication in the internet; participants multi-professional specialists (n = 17); palliative care physicians (n = 5); medical oncologist (n = 1); general medicine physician (n = 1); psycho-oncologists (n = 3); sociologists (n = 2); medical ethicist (n = 1); expert on Delphi methodology (n = 1)	• family care as one central domain of documentation: family relationships, key person in patient care, family's preference of place of care/explanation of medical condition, explanation of medical condition to patient or family, expectations of family, discussion about a do-not-resuscitate order, explanation to family about: course of disease until death, patient's impending death, one week prior to death, care strategy for family

5. CONCLUSIONS

Documentation related to family nursing is quite scarce. This may partly demonstrate how health care staff feel about the family as a collaborative companion in patient care. On the other hand, it may also demonstrate deficiencies in documentation in general. This could be improved by means of basic and continuing education and by developing practices and working conditions which enable a family presence and involvement in patient care and, consequently, related documentation. With comprehensive documentation, involving the patients and their families, the quality and continuity of care can be improved. In addition, more research is needed in order to improve family documentation.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflict of interest.

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