



Supportive nursing care for family caregivers – A retrospective nursing file study

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ABSTRACT

Background: Family caregivers enable patients to be cared for and die at home whereas nurses aim to support the family caregivers of these patients. Information on how this support is provided and how this is documented in nursing files is largely lacking.

Aim: To gain insight in nurses' reports on the supportive care for family caregivers.

Methods: We studied 59 nursing files of adult patients who had received hospice home care in the Netherlands from 4 home care organisations between August 2017 and October 2018. Information on supportive nursing care for family caregivers was retrieved from the nursing files based on a prestructured form. Data was quantitatively and qualitatively analysed.

Results: 54 out of 59 nursing files contained information about family caregivers; 40 files contained nursing diagnoses on family caregivers and in 26 files nursing interventions on supportive care for family caregivers were reported.

Conclusion: Only half of the nursing files contained information about supportive nursing care for family caregivers. Complete nursing documentation of provided care to family caregivers is needed.

1. Background

In many countries the majority of people prefer to die at home (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). In 2017 one out of three deaths occurred at home in the Netherlands, i.e. 50.000 persons (CBS, 2019). To enable the possibility of dying at home, family caregivers (FCGs) play a crucial role. FCGs can be defined as: 'individuals who provide any physical, emotional and instrumental support or assistance to individuals with a life-limiting illness that they view as family members' (Stajduhar et al., 2010). Just like the patients, many FCGs report home as the preferred place to care for their relatives during the last phase of life (Woodman, Baillie, & Sivell, 2016). Besides providing care for their relatives, which may be valuable for both the FCGs and the patient, FCGs can be confronted with different aspects of caregiver burden, such as physical symptoms, psychosocial distress, impaired social relationships, spiritual distress, financial crisis, role strain, disruption of daily life and uncertainty (Choi & Seo, 2019). From a professional point of view,

nurses are in a unique position to support FCGs at home (Lambregts, Grotendorst, & van Merwijk, 2016). They play an important role in the promotion and advancement of early palliative care for patients and families, and in the delivery of palliative nursing care to individuals and families (Fitch, Fliedner, & O'Connor, 2015). Two domains of support for FCGs can be distinguished: (1) support for the FCG to provide care (co-worker) and (2) psychosocial support to improve the wellbeing of the FCG (co-client) (Ewing & Grande, 2013). In recent years, nursing interventions related to FCGs have received growing attention. A recent review shows that nursing interventions can have a positive effect on FCGs' outcomes (Becqué, Rietjens, van Driel, van der Heide, & Witkamp, 2019).

In the Netherlands a physician's assessment that a patient is in the terminal phase of a life-limiting disease is required for the reimbursement of hospice care by health insurance companies. From that moment onwards, patients and FCGs may choose to go to a hospice and/or to receive hospice care at home (Harder, Zilverentant, & Oonk, 2019).

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Until 2020 this initially concerned a period of three months that could be extended by a reassessment. Home hospice care is provided by nurses and nursing assistants and should be tailored to the personal individual needs of the dying patient and his FCGs (Epstein & Street, 2011). Nurses are responsible for the assessment of patients' and FCGs' needs for home care and for the assignment of hospice care at home. To achieve this, nurses need to follow the cyclical method of the nursing process for both the patient and the FCGs (Alvaro-Lefevre, 2014), including needs assessment, diagnosing, planning, implementation and evaluation of care (Huitzi-Egilegor, Elorza-Puyadena, & Asurabarrena-Iraola, 2017).

The results of nurses' decisions on diagnoses and planned care, and their notes on provided care are documented in the nursing files, including the patient's background information, assessment forms, nursing care plans and progress notes. Supportive care for FCGs of patients receiving hospice home care is usually documented in the file of the patient, as this supportive care is related to the needs of and care for the patient.

To systematically assess the needs of patients and FCGs and to plan for their care, many home care organisations use the Omaha classification or the North American Nursing Diagnosis Association (NANDA). The Omaha classification consists of a problem classification scheme with 42 problems in four domains (environmental, psychosocial, physiological and health-related behaviours). For each problem 75 different actions can be selected (Martin, 2005). Conversely, NANDA is a classification for nursing diagnoses to support clinical reasoning for nurses. The classification includes thirteen health domains with 235 different nursing diagnoses. Each diagnosis consists of a diagnostic label (often the problem), determining characteristics (often the symptoms) and related factors (etiology) (Herdman & Kamitsuru, 2017). In addition to the NANDA diagnoses, matching interventions and outcomes are classified in the Nursing Intervention Classification and respectively, the Nursing Outcome Classification.

Both the Omaha and the NANDA classification include broad opportunities to describe problems or diagnoses, domains and actions related to FCGs, like support in household chores, support in care tasks or support in decision making on the patients' treatment.

The aim of this study is to gain insight in the supportive care for FCGs that nurses report on. Accordingly, we studied the nursing files of patients assigned for hospice home care.

2. Research methods

2.1. Design and setting

This study is part of the InCaSu@home project, acronym for Informal Caregiver Support at home, and is aimed to improve nurses' supportive care for FCGs of patients receiving hospice home care. Twelve home care organisations in the Netherlands, participating in InCaSu@home, were invited to participate in this retrospective nursing file study. Ten organisations intended to participate; in the end four remained for this study. One out of these four organisations characterised their care as specialised hospice care, while the others delivered generic care, occasionally including hospice care. All nursing files were selected by the home care organisations based on the following inclusion criteria: (1) the patient had received hospice home care between January 1st and July 1st 2017 (life expectancy of less than three months as assessed by a physician), (2) the patient's age was 18 years or older.

2.2. Data collection

We developed a form to extract data from the files, including patient characteristics (gender, age, time from assignment to hospice care until death [in days], diagnosis and place of death), FCGs' characteristics (the number of involved FCGs, the relation of the FCG(s) with the patient, gender and age of the FCGs), and supportive nursing care interventions for FCGs following the five phases of the nursing process (needs

assessment, diagnoses, planning, implementation and evaluation). If patients who met the criteria for inclusion were still alive at the moment of data collection, we retrospectively collected data until the date of data collection. We also registered which classification system (Omaha and/or NANDA) was used, and which problems, domains or diagnoses nurses reported for FCGs. Information about the planning and implementation of supportive care for FCGs was collected from the nursing care plans and the progress notes in the nursing files. The study was conducted in accordance with Dutch law on privacy, therefore anonymity criteria were met. According to Dutch law, this file study was exempt from approval by the Central Committee on Research Involving Human Subjects (CCMO, n.d.), because no interventions with patients or FCGs or other burdensome procedures occurred. Data from nursing files were anonymised in our data form. Initially, data were collected by two researchers to test the form, while another researcher collected the remaining data. All data were collected between August 2017 and October 2018.

2.3. Analysis

Both quantitative and qualitative methods were used to analyse the data. Descriptive statistics were used to summarise demographic data about patients and FCGs and to describe the findings on assessments and diagnoses. Mean scores and standard deviations were calculated for normally distributed data and medians and interquartile ranges (IQR) for non-normally distributed data. Analyses were performed using SPSS version 25. Documentation on the planning and implementation of interventions and on the evaluation of care was qualitatively analysed and discussed by three researchers through open and axial coding techniques.

3. Results

3.1. Patient characteristics

A total of 59 nursing files were studied with a range of 8 to 23 per organisation. Thirty-one (52%) were of female patients and 28 (48%) of male patients. The median age of the patients was 75 (IQR 67.5–83.5). Most patients were diagnosed with cancer (66%), heart failure (10%), neurological diseases (5%) (e.g. ALS or Parkinson) or lung diseases (3%) (e.g. COPD or lung fibrosis). Seven patients were diagnosed with other diseases (12%), such as renal failure, Crohn's disease and infections. For two patients the diagnosis was unknown. The place of death of the patients was at home ($n = 45$), in the hospital ($n = 1$) or in a hospice ($n = 1$). Of five patients the place of death was unknown and seven patients were still alive during this study. Patients died at a median of 21 days (IQR 4–62) after they were assigned to hospice care (see Table 1).

3.2. Family caregivers

From all 59 nursing files, 54 contained information about who the FCGs were and how they related to the patient. In total 35 spouses/partners, 44 children and 4 other FCGs were reported on as being involved in the care for patients. In 29 nursing files, only one FCG was reported on, either the spouse/partner ($n = 19$) or the child ($n = 8$) of the patient. In 17 nursing files, two FCGs were reported on (spouse/partner $n = 11$, child $n = 21$). Eight nursing files contained information about three to four FCGs (spouse/partner $n = 5$, child $n = 15$). Of all FCGs involved, 48 were women and 32 were men (see Table 2). The ages of the FCGs were described in only five files.

3.3. Assessment, nursing diagnoses and classifications on FCGs' needs

Three home care organisations used the Omaha classification to assess and classify problems for FCGs, whereas one organisation used the NANDA classification to base diagnoses on.

Table 1
Patient characteristics (N = 59).

Gender	
Male (%)	28 (47.5%)
Female (%)	31 (52.5%)
Median age (years) at death (IQR ^a)	75 (67.5–83.5)
Days until death from the moment of assignment to hospice care (Median, IQR)	21 (4–62)
Diagnosis (%)	
Cancer	39 (66%)
Heart failure	6 (10%)
Neurological diseases ^b	3 (5%)
Lung diseases ^c	2 (3%)
Unknown	2 (3%)
Other ^d	7 (12%)
Place of death (%)	
Home	45 (76.3%)
Hospice	1 (1.7%)
Hospital	1 (1.7%)
Unknown	5 (8.5%)
Not applicable	7 (11.9%)

^a Interquartile range.

^b Parkinson's disease, Amyotrophic lateral sclerosis, Stroke.

^c COPD, Pneumonia, Lung fibrosis.

^d Infections (aorta, hip), renal failure, Crohn's disease, Addisons Disease.

Table 2
Family caregiver(s) characteristics (relationship patient and gender).

FCGs ^a → FCGs per patient ↓	Spouse/ partner	Child	Other	UK ^b	Gender (M/F/ UK) ^c
1 FCGs (n = 29)	19	8	1	1	10/19/0
2 FCGs (n = 17)	11	21	1	1	14/20/0
3 FCGs (n = 8)	5	15	2	2	8/9/7

^a FCGs = Family Caregivers.

^b UK = Unknown.

^c M/F/UK = Male/Female/Unknown.

The nurses in one of the organisations used the caregiver strain index (CSI) to assess potential caregiving concerns in FCGs. The CSI is a 13-item tool that measures strain related to care provision (maximum score is 13). Positive responses to seven or more items on the index indicate a greater level of strain (Robinson, 1983). The CSI was used by nurses in 10 FCGs out of 23 nursing files from this organisation. The median score of the CSI was 12 (IQR 10–12).

In 40 out of 59 files, nurses reported on diagnoses, problems or needs of FCGs (see Box 1). In the three home care organisations that used the Omaha classification, they sometimes documented NANDA diagnoses in addition.

All documented problems based on the Omaha classification regarded the 'psychosocial domain', focusing on problems with 'caretaking' of the FCGs. Nursing interventions or actions matching with these problems concerned 'end-of-life care', 'coping skills', 'communication', 'continuity of care', 'spiritual care' and 'physical signs and symptoms'.

All NANDA diagnoses that were reported on FCGs, regarded the domain 'role relationships'. Within this domain ten diagnoses were categorised as 'caregiver role strain', defined as: 'difficulty in performing the caregiver role'.

To determine the characteristics (symptoms) of the 'caregiver role strain', the diagnosis included three themes: the caregiving activities, the FCGs' health status, and family processes. Most of the reported characteristics concerned caregiving activities, such as difficulties to complete and perform (care) tasks (9×) and preoccupation of FCGs with care routine (3×). Other characteristics reported on were 'apprehensiveness about future ability to provide care', 'apprehensiveness about future care receiver' and 'dysfunctional change in caregiving activities'.

Regarding the health status of the FCGs, the symptom 'fatigue' was reported on. Regarding family processes, 'concern on family members' was mentioned.

Related factors (etiology) matching the diagnosis of 'caregivers' 'role strain' that were reported on included four themes, i.e. the FCGs' health status, the caregiving activities, the resources and the patient's health status. Most of these reported factors were about the FCGs' health status, such as their 'physical condition' and 'insufficient fulfillment of others' expectations'. Secondly FCGs' caregiving included 'around-the-clock care responsibilities', 'complexity of care activities' and 'excessive caregiving activities' (see Box 1).

3.4. Planning and implementation: nursing care plans and progress notes on FCGs

In the majority of the nursing files information about planning and implementation of supportive care for FCGs was lacking. In 26 nursing files at least some information concerning FCGs was documented in the nursing care plans and the progress notes (see Box 2).

One of the most reported issues was the presence of FCGs in the patient's network, often generally reported in terms of relationship to the patient and involvement in patient's care. For example: *'The patient receives care from her spouse, also her children provide support when needed'*.

Furthermore nurses report on a diversity of activities of FCGs which can be summarised into four categories: household chores, care activities, emotional support, and communication with healthcare providers. 'Household chores' concerned the documentation of all the chores that may be fulfilled by FCGs in and around the patient's house. For example: *'The spouse is present with the patient. Groceries and household chores are all done by the spouse'*. 'Care activities' included practical support FCGs provide to the patient with food and drink, medication uptake, wound care, going to the bathroom and changing the patient's bed linens. A nurse reported: *'The daughter does the wound care, changes the bed linens, cares for food and drink and the medication uptake'*. The third theme concerns how emotional support is given by the FCGs to the patient. For example, nurses describe how FCGs communicate in an open manner with the patient, and how families experience each other's support. A nurse reported: *'With her sister and nephew she can openly talk about the illness trajectory'*. The last theme is about communication task of the FCGs. In a few files, nurses had documented on the contact of FCGs with the general practitioner, for example that the FCGs were informed on the medical condition of the patient by the general practitioner. A nurse reported: *'The General Practitioner spoke with the children about palliative sedation'*.

Besides the presence of FCGs and their tasks, nurses reported on the needs and questions of FCGs. Three themes were distinguished, i.e. the physical symptoms related to diseases of the FCGs, FCGs' burden, and future care. Nurses documented on the FCGs' own diseases, like cancer, stroke, arthrosis and fatigue. This was documented either to argue that FCGs were not able to fulfill tasks for the patient or to report on a talk with the FCGs about their health problems. Regarding FCGs' burden, nurses referred to the Caregiver Strain Index, or generally documented on the burden, such as that the FCG had said she felt very tensioned, the FCG looked tired or worried about the future. Regarding 'future care' nurses documented on the wishes of the FCGs for (palliative) end-of-life-care. For example, nurses reported on FCGs who were seeking for (specific) care for the patient (e.g. care during the night, a request for consult of a palliative care team), the signing of a do-not-resuscitate order, and on the planning of a euthanasia trajectory.

3.5. Planning and implementation: care pathway for the dying patient

One organisation used a care pathway for dying patients in home care settings (IKNL & Erasmus MC, 2011) based on the Liverpool Care Pathway for the dying patients (Ellershaw & Murphy, 2003). The care

Box 1

Classifications and diagnoses related to FCGs.

Omaha classification (N = 24)

Domain

Psychosocial (N = 24)

Problems

Caretaking (N = 24)

Actions related to/focusing on FCGs

End-of-life care (N = 6)

Coping skills (N = 3)

Communication (N = 2)

Continuity of care (N = 1)

Spiritual care (N = 1)

Signs and symptoms physical (N = 1)

Unknown (N = 10)

NANDA classification (N = 16)

Health Domain

Role relationships (N = 16)

Diagnosis

Caregiver role strain (N = 10)

Missing (N = 6)

Determining Characteristics

Caregiver health status:

Fatigue (n = 1)

Caregiving activities:

Preoccupation with care routing (n = 3)

Apprehensiveness about future care receiver (n = 1)

Apprehensiveness about future ability to provide care (n = 1)

Dysfunctional change in caregiving activities (n = 1)

Difficulty completing and performing tasks (n = 9)

Family processes:

Concern on family members (n = 1)

Related Factors (etiology)

Caregiver health status:

Physical conditions (n = 3)

Insufficient fulfillment of others' expectations (n = 4)

Care receiver health status:

Illness severity (n = 1)

Caregiving activities:

Around-the-clock care responsibilities (n = 5)

Complexity of care activities (n = 4)

Excessive caregiving activities (n = 4)

Resources:

Inexperience with caregiving (n = 2)

N = the number nursing files n = the number of times scored.

Box 2

Issues and themes in nursing documentation:

1. The presence of FCGs

2. The tasks of FCGs

- Householding chores
- Care activities
- Emotional support
- Communication with health care providers

3. The needs and questions of FCGs

- Physical symptoms of FCGs
- Burden of FCGs
- Future care

pathway was used in the last days or hours of life once it was known that patients were dying. In addition to paying attention to the dying patient, the care pathway enabled health care professionals to take note of the FCGs by checking different statements regarding FCGs. In the care

pathway, a total of 11 statements were made on FCGs (e.g. 'FCGs can actively participate in the conversation', 'FCGs know that the patient is dying' and 'FCGs have been given the opportunity to discuss what is currently important to them'). In this organisation, the care pathway

was used in seven out of 23 patients that had died, and in six of them the statements on FCGs were checked: all 11 statements in one CP, and at least seven in the other CPs.

3.6. Evaluation of care for FCGs

None of the nursing files included notes on the evaluation of the supportive care for FCGs.

4. Discussion

This retrospective file study showed that nurses identify FCGs and how they relate to patients. In most nursing files, NANDA, OMAHA or the Caregiver Strain Index (CSI) were used to diagnose and/or classify problems of FCGs. In general, the identified diagnoses concerned the 'psychosocial' and 'role of relationship' domains. More specific the diagnoses concerned the needs of FCGs as caregiver (caregiving activities) and on their personal health (caregiver health status). When the CSI was used, nurses identified burden of FCGs. Appropriate interventions in response to the diagnosis were scarcely described and were mostly an extension of diagnosis descriptions, focusing on FCGs' tasks (household chores, support of care tasks, emotional support and communication tasks) and problems (physical complaints, burden). A care pathway for the dying patient was only used in a few files, guiding nurses how to support FCGs in the last days or hours of a patient's life.

4.1. Co-worker and co-client

Twigg (1989) describes that FCGs can be seen as co-worker and co-client; both roles emerge in our study and were also described in other research (Ewing & Grande, 2013). The role of co-worker was mentioned in the diagnoses, where nurses emphasised the ability of FCGs to care for their relatives (caregiving activities) and in the nursing reports, where FCGs' tasks like household chores and support of care tasks were reported. Caring for relatives can affect FCGs' lives in various ways. On the positive side, FCGs report high levels of reward, such as feelings of being helpful to the patient, giving something to the patient that brought them happiness. To a lesser extent, the feeling of reward is further related to personal growth, self-satisfaction and personal meaning (Henriksson, Carlander, & Årestedt, 2015). On the other hand, FCGs can experience a considerable burden from caregiving which may affect both the FCG and the patient negatively (Grande, Rowland, van den Berg, & Hanratty, 2018; Wolff, Dy, Frick, & Kasper, 2007), which may place FCGs on the co-client role. In our study the co-client role emerged from nursing files reporting FCGs' needs for personal support (caregiver health status), physical complaints and experienced burden. The variety of FCGs' problems, wishes and needs urge nurses to identify their characteristics before being able to properly support FCGs with nursing interventions (Becqué et al., 2019).

4.2. Assessing the needs of FCGs

In our study the FCGs' needs were not systematically assessed. Only nurses of one organisation used an assessment tool for strain and burden related problems (the CSI). This is remarkable because various valid and reliable tools are available to assess the different aspects of the caregiving experience, particularly caregiver burden, the needs of FCGs and quality of life (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). Furthermore, assessment tools focusing on family caregiving in the palliative care setting are available (Hudson et al., 2010). A benefit of using assessment tools is that the outcomes may provide a basis for dialogue between nurses and FCGs and therefore foster a deeper exploration of the FCGs' experience and their needs. Web-based programs and/or smartphone applications can possibly contribute to this in the (near) future (Heynsbergh, Heckel, Botti, & Livingston, 2018).

4.3. Nursing documentation

The nurses in our study nevertheless identified various needs/problems of FCGs, and documented the contribution of FCGs to the patient care. However, hardly any documentation was found about either planned and provided supportive interventions or the evaluation of provided support to FCGs. Inadequate reporting has also been shown in other studies. For example, a qualitative study among palliative care nurses confirmed a gap in all areas of the nursing process. Incomplete documentation endangers mutual communication between nurses, and continuity of care (Henderson, Vaz, & Viridun, 2018). Additionally, it is known that nurses perform many more caring tasks than they actually document. An observational study showed that only 40% of all nursing activities that were observed were included in the nursing records (De Marinis et al., 2010). Inadequate nursing documentation is not a problem that affects only FCGs. A mixed method systematic review by Wang, Hailey, and Yu (2011) reports a predominance of documentation of biomedical issues and hence insufficient recording of psychological, social, cultural and spiritual aspects of care.

Furthermore, information about the FCGs was documented in patients' files. Therefore FCGs may not receive the attention they deserve. This is also recognised in a study of Grande, Austin, Ewing, O'Leary, and Roberts (2017), addressing the possibility of a separated FCG file.

4.4. Strengths and limitations

To understand supportive nursing care for FCGs of patients at the end of their lives, studying the documentation of the nursing files is not sufficient, and findings must be interpreted with caution. Non-recorded data limit the ability to provide a full picture of nursing care for FCGs in this setting. A limitation of this study is the selection of only four home care organisations. However, our findings do not deviate from the results of previous research on nursing documentation in patient files (De Marinis et al., 2010; Henderson et al., 2018). The strength of this study is that data collection and data analyses were performed by three researchers, and the outcomes were extensively discussed in the research team.

5. Conclusions

Nurses documented various problems and nursing diagnoses on FCGs, which were rarely identified by available FCGs' needs assessment tools. Furthermore, nurses did not report on planned supportive care to follow-up the identified problems or diagnoses, nor did they report on the evaluation of FCGs' experiences. To systematically support the FCGs of patients at the end of life more accurate and complete nursing documentation is warranted.

Authors agreement

The authors declare that they have seen and approved the final version of the manuscript being submitted. They declare that the article is the authors' original work. It hasn't received prior publication and isn't under consideration for publication elsewhere.

Author contributions

Anne Geert van Driel: Methodology, Formal analysis, Writing – Original Draft **Yvonne Becqué:** Methodology, Formal analysis, Writing – Review & Editing **Judith Rietjens:** Writing – Review & Editing, Supervision **Agnes van der Heide:** Writing – Review & Editing, Supervision **Erica Witkamp:** Conceptualization, Formal analysis, Writing-Reviewing & Editing, Project administration.

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Declaration of competing interest

None.

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