# Supportive Nursing Care for Informal Caregivers - A Retrospective File Study

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# **BACKGROUND**

In the Netherlands many patients receive end-of-life care (EoLC) at home from nurses working for homecare organisations (HCO). Informal caregivers (IC), such as spouses and children, play a significant role in facilitating patients to stay at home. Nurses also aim to support these IC, but information on how this is done is lacking.

#### AIM

To get insight into supportive care for IC as provided by community nurses.

#### **METHODS**

Four homecare organisations were approached to participate in this study. We studied nursing files of patients who received end of life care. A data extraction form was used to collect demographic data of the patient and their informal caregiver(s), and information about supportive nursing care for informal caregivers. The content of documentation on informal caregivers was qualitatively analysed by open and axial coding techniques.

### **RESULTS**

We examined nursing files of 59 patients (28 men and 31 women). Mean age of the patients was 75 years (SD±11). They were diagnosed with cancer (63%), heart failure (10%) or other illnesses (24%) (e.g. neurological or lung diseases). Most patients died at home (76%). Some of them were still alive during this study (14%). The mean time between assignment for end of life care and death was 50 days (±76). The number of involved informal caregivers was one (41%), two (27%), three (10%) or four (2%). In most cases informal care was provided by the patient's spouse (58%) or child (27%).

The homecare organisations used different classification systems to register nursing care. One homecare organisation used NANDA[1], the others used OMAHA[2]. One organisation used the Care Giver Strain Index to assess the needs of informal caregivers. In 68% of all the files some kind of informal caregiver's needs was mentioned in a plan (e.g. overburden).

In general nursing files contained little information on informal caregivers, concerning mainly 4 themes:

- 1. The nature of the social network (e.g. who is involved, how do they (each) contribute to the care),
- 2. Planned or delivered caring activities of informal caregivers (e.g. medication, having nice talks),
- 3. Collaboration of formal and informal caregivers (e.g. mutual expectations, mutual handovers),
- 4. Planned or delivered nursing care for informal caregivers (e.g. providing medical information, instruction, emotional support).

  Effect or process evaluation was not documented.

<sup>1</sup> www.nanda.org <sup>2</sup> www.omahasystem.org



HCO <sup>a</sup>	A n=23 (39%)	B n=17 (29%)	C n=11 (19%)	D n=8 (14%)	Total n=59 (100%)
Gender patients (M/F) <sup>b</sup>	14/9	8/9	3/8	3/5	28/31
Nursing Classification	NANDA	OMAHA	OMAHA	OMAHA	
Nursing Plan IC <sup>c</sup>	18 (78%)	11 (65%)	9 (82%)	4 (50%)	42 (71%)

- a. Home Care Organisation
- b. (M/F) = Male / Female
- c. IC = Informal Caregiver(s)

# CONCLUSION

In almost two thirds of patients receiving end of life care at home, nurses documented some supportive needs of informal caregivers. Documentation of how nurses meet the needs of informal caregivers and evaluation of these interventions was scarce. This poses a risk for the quality and continuity of supportive care for informal caregivers.

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