

# How do nurses support family caregivers in end-of-life home care: a qualitative study

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## BACKGROUND

Family caregivers are crucial in end-of-life care at home. Without their care, it would be impossible for many patients to die at home<sup>1</sup>. In addition to providing care family caregivers also need care themselves<sup>2</sup>. Nurses could support family, but their care is usually focused on the patient <sup>3,4</sup>. Little is known about how nurses fulfil their supportive role.

## AIM

The aim of this qualitative study is to explore how nurses currently approach and support family caregivers in end-of-life home care.

## METHODS

Data were collected using semi-structured qualitative interviews with 14 nurses from nine home care organisations in the southwest region of the Netherlands, from March to August 2018. Interviews were audio-taped and the transcribed texts were analysed using a thematic analysis approach.

## RESULTS

Table 1 Characteristics of the interviewed nurses (N= 14)	
Female	N=12
Age	Mean 45 years (range 23-59)
Working experience as a nurse	0-39 years

All interviewed nurses pay attention to family caregivers. The most often mentioned supporting activities were: identification of needs, psychoeducation, emotional support and arranging respite care.

Table 2 Four main types of support of family caregivers	
1. Identification of family caregivers’ needs.	
2. Psycho-education divided into:	
• Educational support about e.g. the patient’s illness and dying process,	
• Support in decision-making about care, treatment and place of death.	
3. Emotional support.	
4. Arranging respite care such as overnight palliative care support, home help and home visits of a volunteer.	

The needs of family caregivers are usually not systematically identified. Many nurses reported that their supporting activities are predominantly based on their intuition and experience. Nurses’ personal preference play a role in the selection of supportive interventions. Nurses indicated various factors which affect - either positively or negatively- their approach to and support of family caregivers in end-of-life care.

Table 3 Influencing factors of nursing support		
Micro: individual level	Meso: organisation level	Macro: society level
- Nursing competence	- Organisation of care (general vs specialized palliative care)	- Societal and policy developments
- Beliefs and values of nurses	- Participation palliative care network	- Laws and regulations (e.g. health insurance law)
- Beliefs and values of family caregivers	- Collaboration with other health care professionals	- Availability of services
		- Registration systems

## CONCLUSION

Nurses aim to support family caregivers. However this support is not systematically offered and mainly based on intuition and experience, which involves the risk that family caregivers’ needs will be missed. More emphasis is needed on the development and utilization of evidence based family caregivers’ needs assessment tools and supportive interventions. For nurses working in the complex end-of-life home care context, it is a challenge to respond to the needs of family caregivers.

## REFERENCES

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