

Symptoms and stress in family caregivers of ICU patients

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Why are the family caregivers so important for the patients?

- Family caregivers are essential for the patients in their recovery
 - Communication
 - Feel understood
 - Feel safe
 - Motivated in their struggle to survive critical illness



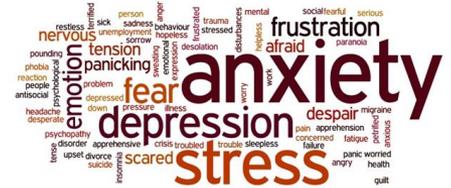
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Engström Å et al. (2007). Receiving power through confirmation: the meaning of close relatives for people who have been critically ill. *J Adv Nurs*, 59(6):569-576.
Price AM (2004). Intensive care nurses' experiences of assessing and dealing with patients' psychological needs. *Nurs Crit Care*, 9(3):134-142.
Hoorn et al. (2016). Communicating with conscious and mechanically ventilated critically ill patients: a systematic review. *Crit Care* 20:333.
Davidson JE et al. (2012). Family response to critical illness: Post-intensive care syndrome-family. *Crit Care Med* 40(2) pp 618-624

Quotation from a patient

«It was like they gave me power in some way, because sometimes I felt like: God, if I could fall asleep forever. I felt that many times, the mornings especially were terribly hard... if I hadn't had my close relatives, I don't know how I would have managed it»

Engström, Å, Söderberg Siv (2007). Receiving power through confirmation: the meaning of close relatives for people who have been critically ill. Journal of advanced nursing 59(6). 569-576.

The history of symptom research in family caregivers of ICU patients



- Research on symptoms in family caregivers started in the early 1970
- In the 1990 researchers began to understand that family caregivers could experience psychological burden related to the situation as caregivers

McAdam J, Puntillo K (2009). Symptoms experienced by family members of patients in intensive care units. *American Journal of Critical Care* 18(3) pp 200-210.

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Van Beusekom et al. (2016). Reported burden on informal caregivers of ICU survivors: a literature review. *Crit Care* 20:16.

Davidson JE et al. (2012). Family response to critical illness: Post-intensive care syndrome-family. *Crit Care Med* 40(2) pp 618-624

Format: Abstract ▼

J Pain Symptom Manage. 2017 Aug 29. pii: S0885-3924(17)30424-4. doi: 10.1016/j.jpainsymman.2017.08.018. [Epub ahead of print]

Multiple Symptoms in Family Caregivers of Intensive Care Unit Patients.

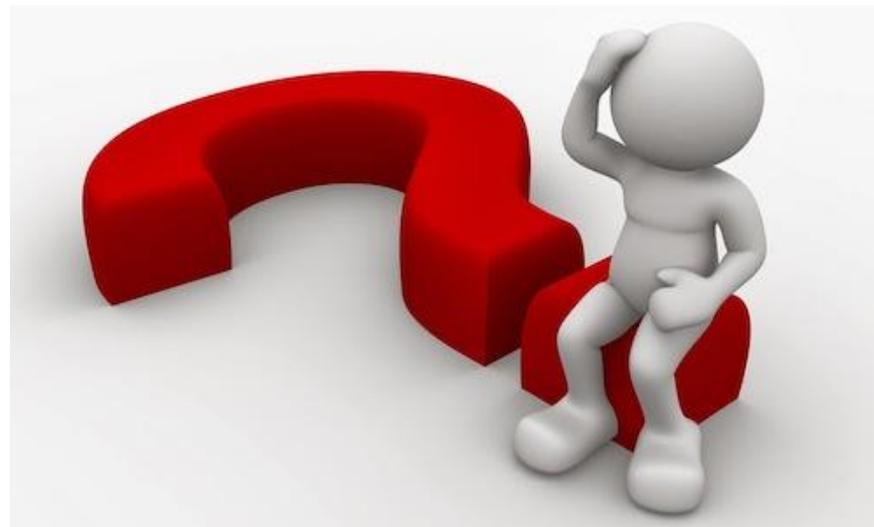
Alfheim HB, Rosseland LA, Hofsvø K, Småstuen MC, Rustøen T.

KEYWORDS: Family caregiver; intensive care; multiple symptoms; quality of life; worrying

PMID: 28864399 DOI: [10.1016/j.jpainsymman.2017.08.018](https://doi.org/10.1016/j.jpainsymman.2017.08.018)

Research questions

1. Describe occurrence, severity and distress of multiple symptoms in FCs of ICU patients
2. Identify the association between FC's background characteristics and number of symptoms



Method (N=211)

- Symptoms from “Memorial Symptom Assessment Scale” at baseline (at admission to the ICU)
- Recruitment from four different ICUs (2013-2015)
- **Family caregivers** (> 18 years, understand Norwegian, mentally healthy, ≤ 2 family caregivers per patient)
- **Patients** (> 18 years, length of stay > 24 hours, understand Norwegian, previous mentally healthy)



DIRECTIONS: We have listed 32 symptoms below. Read each one carefully. If you **DID NOT HAVE** the symptom in the **past week**, make an “X” in the column marked “DID NOT HAVE.”

If you had the symptom in the **past week**, then write the **SEVERITY** of the symptom in the **SEVERITY RATING** column using the yellow 0 to 10 **SYMPTOM SEVERITY SCALE** below.

In addition, write how much the symptom **DISTRESSED OR BOTHERED** you in the **DISTRESS RATING** column using the green 0 to 10 **SYMPTOM DISTRESS SCALE** below.

Symptom Severity Scale

| | | | | | | | | | | |
|------|---|------|---|---|----------|---|---|--------|---|-------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| none | | mild | | | moderate | | | severe | | intolerable |

Symptom Distress Scale

| | | | | | | | | | | |
|------------------------|---|--------------------------|---|---|----------------------|---|---|-------------------------|---|------------------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| not at all distressing | | a little bit distressing | | | somewhat distressing | | | quite a bit distressing | | very distressing |

| <u>DURING THE PAST WEEK,</u> Did you have any of the following symptoms? | Did not Have | Severity Rating | Distress Rating |
|---|--------------------------|-----------------|-----------------|
| Difficulty concentrating | <input type="checkbox"/> | | |
| Pain | <input type="checkbox"/> | | |
| Lack of energy | <input type="checkbox"/> | | |
| Cough | <input type="checkbox"/> | | |
| Feeling nervous | <input type="checkbox"/> | | |
| Dry mouth | <input type="checkbox"/> | | |

Background characteristics family caregivers



| Characteristics (n=211) | Median (range) |
|------------------------------------|----------------|
| Age | 50 (19-80) |
| Number of comorbidities | 1 (0-8) |
| | n (%) |
| Gender | |
| Male | 67 (31.8) |
| Female | 144 (68.2) |
| Daily care for children < 18 years | 72 (34.1) |
| Experience with ICU | 111 (53.1) |
| Other life events | 126 (59.7) |
| Cohabitation | |
| Living with someone | 180 (86.1) |
| Living alone | 29 (13.9) |
| Education | |
| Primary/ secondary school | 113 (56.3) |
| College/ university | 98 (46.4) |
| Sick leave | 60 (28.4) |
| Relationship to the patient | |
| Parent | 66 (32.8) |
| Spouse/ partner/ child/ other | 136 (67.2) |

Two most reported symptoms

| Multiple symptoms | Occurrence | Severity (0-10) | Distress (0-10) |
|---------------------------|----------------|-----------------|-----------------|
| | % (n) | Mean (SD) | Mean (SD) |
| Worrying | 91.0 (192) | 7.2 (2.4) | 5.9 (3.1) |
| Feeling sad | 87.7 (185) | 6.5 (2.2) | 4.9 (3.2) |
| Difficulty concentrating | 73.5 (155) | 5.4 (2.0) | 4.0 (2.9) |
| Difficulty sleeping | 70.6 (149) | 5.8 (2.3) | 4.8 (3.0) |
| Feeling nervous | 63.5 (134) | 6.1 (2.5) | 5.1 (3.2) |
| | Median (range) | | |
| Number of symptoms | 9 (0-24) | | |

Family caregiver characteristics associated with increased number of symptoms?

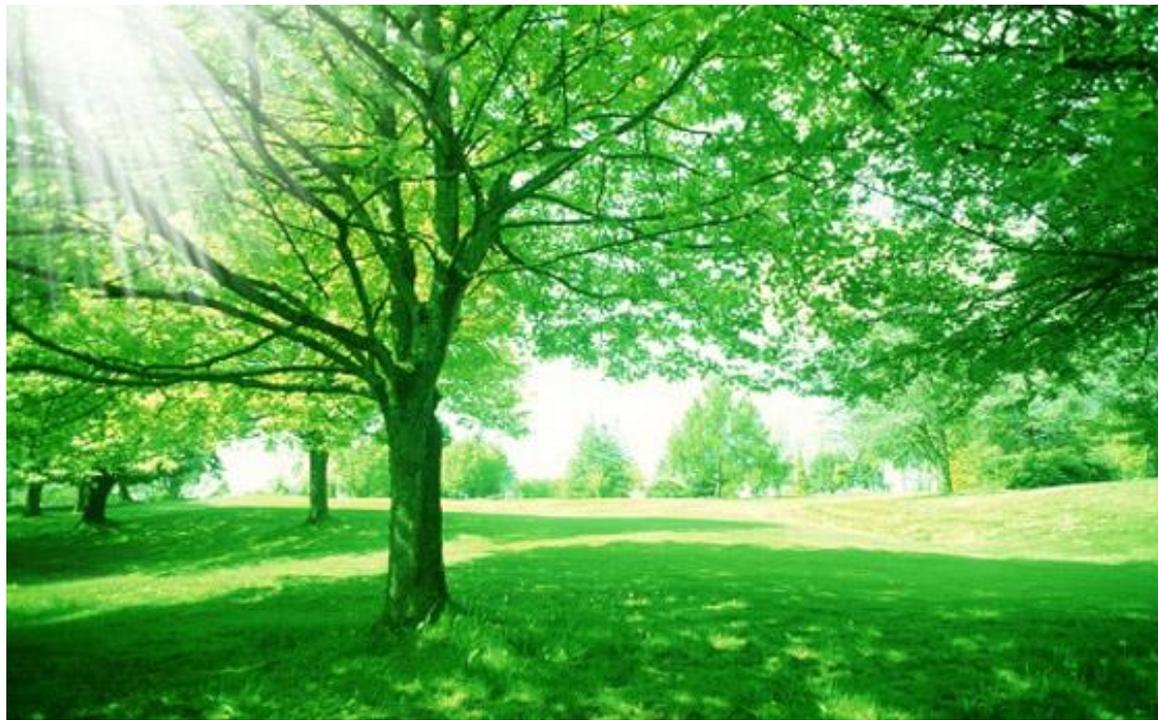


- Number of comorbidities
- Younger family caregivers
- Being a spouse
- Higher education

Conclusion



- Family caregivers experience multiple symptoms
- Mental symptoms are most frequent
- Symptom severity and distress adds important information about the symptom experience
- Be aware of vulnerable groups



Find family caregivers at risk for developing a high symptom burden

Emphasise family centred care

Thank you for your attention

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"There are only four kinds of people in the world -
Those who have been caregivers,
Those who are currently caregivers,
Those who will be caregivers
And those who will need caregivers."

Rosalynn Carter