

Sense of security in palliative home care

Dyadic comparisons of patients' and family members' perceptions

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Sense of security

- symptom relief
- availability of help
- continuity of care
- user-involvement
- information
- cooperation and coordination
- competence of staff
- respect

Background

Family members may feel supported when they know that the palliative care is in accordance with the patients' interests. It is vital that patients and their family members feel secure with the palliative home care for the patients.

Aim

To compare patients' and family members' perceptions of security of palliative home care.

Methods

60 patients receiving palliative home care in Norway and 38 of their family members participated. A patient and family member version of a modified Quality from Patients' Perspectives (QPP)* was used for measuring aspects of security. QPP encompasses 49 items and were answered on following two 4-point Likert-type scales: perceived reality (PR) and subjective importance (SI), ranging from 1 (PR totally insecure/SI of little or no importance) to 4 (PR totally secure/SI of very great importance). EQ VAS** was used to measure health related quality of life on a visual analogue scale from best (100) to worst (0) imaginable health status. SPSS, descriptive statistics and Wilcoxon's signed rank test were used to analyse the data. *P-value* was < 0.05.

* Wilde Larsson, B. & Larsson, G. (2002) Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire. *Journal of Clinical Nursing*, 11(5), (681-687).

** Janssen, MF, Haagsma, JA, Bonse, GJ (2005) Comparing the standard EQ-5D three level system with a five level version. 22nd Plenary Meeting of the Euroqol Group (.98-117).

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Preliminary results

Of the participants, 32 were dyads, patient/family member, with following results:

Patients

19 women and 13 men participated. The mean age was 74 years (51-95), 13 lived alone, 14 didn't know how to get help if something unanticipated happened. More than half were diagnosed with cancer, and many of the participants had several diagnoses in combination. Patients' self-rated state of health (EQ VAS) was 48 (10-90).

Family members

21 women and 11 men participated. The mean age was 60 years (30-89), 21 were in employment and 28 knew how to get help if something unanticipated happened to the patient. Family members' self-rated state of health (EQ VAS) was 79 (35-100).

Patient/family members

Patients'/family members' dyads had high levels of agreement in ratings of PR and SI. There were eight statistically significant differences on the PR scales (family members lower than patients) and four on the SI scales (family members: three higher than patients and one lower). The statistically significant differences, the three highest and the three lowest scores are presented in the table (presenting 17 out of the 49 items).

Table. Patient/family dyads rating of security with palliative home care

Items	Perceived reality			Subjective importance		
	Pat. M(SD)	Fam. M(SD)	P-value	Pat. M(SD)	Fam. M(SD)	P-value
Relieving pain	3.5 (.59)	2.9 (.64)	.020	3.6 (.50)	3.7 (.51)	
Relieving symptoms	2.6 (1.47)	2.7 (.76)		3.6 (.49)	3.7 (.54)	
Best possible care	3.6 (.47)	3.1 (.55)	.008	3.6 (.54)	3.8 (.40)	
Medication in time	3.8 (.32)	3.2 (.63)	.005	3.8 (.37)	3.9 (.28)	
Correct doses of medication	3.3 (.85)	3.1 (.66)		3.7 (.43)	3.9 (.19)	.046
Information on medication	3.6 (.56)	3.3 (.73)	.008	3.6 (.49)	3.6 (.62)	
Information on prognosis	2.7 (1.04)	2.8 (.86)		3.5 (.63)	3.6 (.61)	
Participation in decisions about place of care	3.7 (.56)	3.1 (.76)		3.7 (.53)	3.4 (.65)	
Respected by carers (pat.)	3.7 (.46)	3.6 (.55)		3.7 (.45)	3.8 (.38)	
Respected by carers (fam.)	3.8 (.35)	3.8 (.39)		3.9 (.31)	3.6 (.56)	
Getting honest answers	3.5 (.57)	3.2 (.55)	.033	3.7 (.46)	3.6 (.47)	
Being shown thoughtfulness	3.5 (.62)	3.6 (.54)		3.5 (.57)	3.8 (.35)	.046
Knowing who will give care each time	2.4 (1.03)	2.0 (.97)		2.8 (1.05)	3.2 (.95)	
Treatment from the same physician	3.5 (.65)	3.2 (.76)		3.8 (.38)	3.6 (.47)	.046
Coordination of treatment and care between carers and physicians	3.4 (.66)	2.7 (.93)	.033	3.5 (.74)	3.6 (.56)	
Care according to promises from carers	3.7 (.44)	3.3 (.55)	.007	3.5 (.50)	3.7 (.41)	.034
Care according to promises from physicians	3.6 (.49)	3.1 (.73)	.011	3.6 (.49)	3.7 (.41)	

Scale: 1 (Totally insecure/of little or no importance) - 4 (Totally secure/of very great importance).
P-values refer to differences between patients and family members (Wilcoxon's signed rank test).

Preliminary conclusions

The results should be valuable for politicians in developing palliative care services, and may influence health professionals in performing palliative care of high quality and to obtain common care-related experiences of security for patient/family members.

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