Contexts of awareness in end-of-life palliative care: a grounded theory (Research Proyect FFI2016-76927-P- AEI/FEDER, UE)



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Background

Clinical communication with terminally-ill patients guarantees dignity and facilitates decision-making. This communication is not always open and different contexts of awareness have been described. In these contexts, patients may or may not know the extent of their illness and prognosis ('open awareness', 'closed awareness', 'suspected awareness' and 'mutual pretence').

Methodology

A qualitative study based on Grounded Theory was designed. For data collection, ten in-depth interviews were conducted on patients included in palliative care programmes. Data analysis was performed after including the transcription of the interviews and the field notes into ATLAS.ti software for coding. An open, axial and selective coding process was carried out by using the constant comparative method and theoretical sampling.

Aim

The objective of this study was to understand the professional-patient communication process and the awareness contexts established in palliative care patients.

Conclusion

Patients with far-advanced diseases perceive that care in hospital emergency departments is characterised by neglect, deficiencies in information and clinical communication, and the absence of empathetic care. All of this adds to the perception of loss of dignity in end-of-life care in emergency departments.

Results

The following central category emerged:

Patients' pristine struggle to live prevents full acceptance of finitude and death.

Three categories explain this central category:

- (1) Fear compromises the dignity of the person up until their final moment.
- (2) The state of open awareness liberates the communicative process of the person.
- (3) When facing death, a process of confrontation takes place that fluctuates between acceptance and denial.

References

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