Abstract Ljubljana

Proximity, diaries and follow-up services to bereaved family members in Swedish ICUs. Results from a national survey

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Complicated grief and post-traumatic stress symptoms are commonly reported in bereaved ICU family members. Compassionate nursing care, a family-friendly ICU environment and good communication are all important aspects of excellent end-of-life (EoL) care in the ICU. A follow-up service could be an additional way to relieve complicated grief and prevent post-traumatic stress symptoms. This service is implemented in some ICUs but its existence varies throughout Europe as well as globally.

A questionnaire was designed to cover the following issues: Are follow-up meetings offered in your ICU? How and when are family members invited, which professions participate and what do the follow-up services include? Questions on frequencies of patient diaries, privacy in single patient rooms at end-of-life and routines concerning family presence in resuscitation situations were also included.

The survey was sent to 81 ICUs in Sweden and 73 % answered (response rate 90%). 75 % of the ICUs offer some kind of follow-up to family members but routines varies. Critical care nurses where those who most often contacted and initiated the follow-ups. 33% offered solely phone calls; the rest offered a visit to the ICU including diverse activities. 98 % of Swedish ICUs keep patient diaries, 9 % invite relatives to be present during lifesaving activities (e.g. CPR) and 40 % of respondents estimated that patients not had privacy at end of life.

In comparison to an earlier study a positive trend can be seen over time but still many ICUs do not offer privacy or proximity to families at end-of-life and follow-up services for bereaved family members is not fully implemented. These results pay attention to the need of guidelines both nationally and internationally. Proactive EoL-care and structured routines for follow-up and support can presumably alleviate family members suffering and thereby prevent development of complicated grief and illness.