

**Bråd död när patienten drabbats av stroke –
Vårdares och närståendes upplevelser**

Akademisk avhandling
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av

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- I Rejnö Å., Danielson E. & von Post I. (2012). The unexpected force of acute stroke leading to patients' sudden death as described by nurses.
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- II Rejnö Å., Berg L. & Danielson E. (2011). Ethical problems: In the face of sudden and unexpected death.
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- III Rejnö Å., Danielson E. & Berg L. Strategies for handling ethical problems in sudden and unexpected death.
(Inskickad 2012)
- IV Rejnö Å., Danielson E. & Berg L. Next of kin's experiences of sudden and unexpected death from stroke: - a study of narratives.
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- V Rejnö Å., Berg L. & Danielson E. The narrative structure as a way to gain insight in experiences: one methodological approach.
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UNEXPECTED SUDDEN DEATH WHEN THE PATIENT IS AFFECTED BY STROKE- EXPERIENCES OF THE CARERS AND NEXT OF KIN

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Abstract

A large number of people die from stroke every year, many of them suddenly and unexpectedly as a result of acute stroke. Sudden and unexpected death influences the next of kin and carers as well as the care given to the patients but has not previously been studied within the context of stroke.

Aim: The overall aim of the thesis was to describe how carers and next of kin experience patients' death when the patient has been afflicted by stroke.

Methods: In the thesis an interpretive qualitative approach has mainly been used. The studies (I-V) have emerged from one another as in a hermeneutic design. An inductive design (I, II, IV, V) and a deductive design (III) have been used. Data were collected with individual interviews (I, III, IV) and individual interviews together with a form (III). Focus group interviews have also been used (II). Participants have been carers on stroke units; ten registered nurses (I) and nineteen respective fifteen members of stroke teams; physicians, registered nurses and enrolled nurses (II, III) together with twelve next of kin to eight patients (IV, V). For analysis of data mainly interpretive methods were utilized; hermeneutic textual interpretation (I), interpretive content analysis (II) and a combined qualitative and quantitative content analysis (III). In addition narrative thematic analysis (IV) and narrative structural analysis (V) were also used.

Results: Unexpected sudden death when the patient has been afflicted by stroke can be understood as the unexpected force that intervenes without the patient, the next of kin or the carers being prepared (I). The sudden onset puts the carers in ethically demanding situations through the demands of immediate caring for the patient and also the support the next of kin needs, required by the urgent incident (I - III). The ethical problems became most evident in information, decisions about care and caring, together with support for the next of kin (II). The carers did not use ways of handling ethically problematic situations in the same way as they would have preferred. Mutual trust, both within the teams and with the next of kin constitutes the core for the carers ways of handling the urgent situation and the ethical problems guided by putting what's best for the patients first (III). The studies with the next of kin reveal how complex and elusive the situation might be perceived. The next of kin's experiences of the unexpected sudden death were marked by the uncertainty in the situation and to be left to the mercy of the unexpected (IV). The attention of the next of kin was clearly directed to the patient to the extent that they even forgot themselves and their own needs. The urgency shows itself as influencing the way the next of kin experienced time, how their attention was directed during vigil but it also affected their memory so it behaved in a betraying and contradictory way (IV).

Conclusion: Through the results death caused by acute stroke emerge as unexpected sudden death. Unexpected sudden death shows as death calling for urgent actions, brings a potential power to violate the dignity of the afflicted, creating ethical problems that the carers have to deal with and have the power to completely invade the next of kin's present life. The unexpected sudden death brings with it an element of uncertainty that all involved in the situation, the patient, their next of kin and the carers have to address themselves to. Bereavement counselling could be a way to support the next of kin. The methods of this thesis have given knowledge of narrative structure and how it can be utilized to develop stories could be used as a tool for caregivers support the next of kin.

Keywords: carers, combined qualitative and quantitative content analysis, content analysis, dignity, hermeneutic textual analysis, narratives, next of kin, qualitative methods, sudden and unexpected death, uncertainty, stroke, stroke team