

Involvement of the bereaved in the supervisory investigation of unexpected deaths – A development project

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Over the last few years, the supervisory investigations of severe adverse events in Norway such as unexpected deaths have been criticized by the bereaved. Several deaths have been high-profile cases in the national media. The County Governor of Oslo and Akershus oversees healthcare services in two Norwegian counties with around 1.2 million inhabitants. Annually, up to 120 unexpected deaths in healthcare are referred to this office for further investigations. As a response to the demands for stronger user involvements in the supervisory follow up of such deaths, the Norwegian Board of Health Supervision funded a development project over two years (2017-2018) at the office of the County Governor of Oslo and Akershus. We designed a new user involvement method whereby bereaved relatives who had experienced the loss of a close family member in an adverse event were given an opportunity to participate in a two-hour face-to-face meeting with the inspectors. The meeting takes place as part of the supervisory investigation, in order to shed light on the adverse event from the bereaved's perspective.

Objectives:

The development project explores the following:

1. Can a single meeting with the bereaved illuminate the events more broadly and provide additional information to the present written investigations?
2. Does such new information from the bereaved change the further handling of the investigations?
3. What positive and negative effects may such meetings result in for the bereaved?
4. What positive and negative effects may such meetings result in for the inspectors?
5. Which changes in the workflow must be implemented for these meetings?
6. Do such meetings change the total workload and time spent for the inspectors in these cases?
7. What types of unexpected deaths are most relevant and suitable for such involvements of the bereaved?
8. Has the death resulted in crises and subsequent needs for healthcare services for the bereaved?

Methods:

This ongoing project aims to include 50 deaths and began in spring 2017. The core project staff at the County Governor's office was one project manager (medical doctor) and five inspectors (lawyers). A project protocol with criteria for inclusion and exclusion was set up and communicated in the County Governor's office. The main inclusion criterion was that the bereaved had observations during the last days or hours prior to the death. Deaths with an obvious cause were excluded. All new cases of death were consecutively reported to the project manager who replied with a recommendation of inclusions or not. Immediately after the meetings with the bereaved, the inspectors filled out an evaluation scheme related to the meeting including new information obtained. The bereaved received two questionnaires: one evaluating the meeting and one evaluating the appeal process when the case was closed and concluded. External researchers were engaged to evaluate how the next of kin and the supervisory inspectors experienced the meeting and how the new involvement method contributed to new information to the supervisory investigation.

Results:

As of March 2018, 40 deaths in total have been included in the project and 22 meetings have been conducted. In most cases, the meetings give new information which changed the future handling of the investigations. The bereaved have primarily positive experiences of the meetings and no major negative effects have been observed so far. Several adjustments of the workflow are, however, needed.

Conclusion:

A two-hour meeting with the bereaved gives new and valuable information. Many of the families are in a deep state of crisis after the death, but the meetings seem to alleviate some of their worries and self-incrimination