

A PROJECT TO DEVELOP INTERVENTIONS TO OVERCOME THE LIMITS OF MEDICINE IN MANAGING THE DYING PROCESS IN ACUTE CARE HOSPITALS

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Duration: 2000 - 2003

Description: This study comprises a number of action research strategies and produced several outcomes to date. The first phase of research consisted of collecting data through ethnographic observation, formal interviews and informal discussions within the intensive care unit. 13 case studies of the trajectories of dying patients have been collected. Interviews have also been conducted with clinicians and allied health outside of ICU. Transcripts and field notes have been used for sense making and analysis conducted by the research team and in collaboration with intensive care management staff in an ongoing series of research meetings. A high degree of concordance was reached between the research team and staff on the initial description of the data. In attending to the patterns of interaction, communication and storytelling, the researcher has developed a 'thick description' of the meanings that staff, patients and families give to the situation. A second phase of focus groups is underway with nurses and doctors within the unit. This second phase, by building on the thematic categories of the first allows for a more subtle and sharply focused questioning.

The emerging systemic analysis of the regularities and patterns of action identifies a complexity of intervening factors including case mix, staffing issues leading to discontinuities of care by staff to patient, tribal conflicts and ownership of patients, technological and heroic imperatives to pursue life saving treatment, and resource constraints. Ordering or mediating structures such as hierarchies of decision making, ward round rituals, diplomacy across teams, clinical nurse educator and team leader roles act to minimize and control for uncertainty, risk, conflict and threats to coherence of the system. Variance across the range of case studies in terms of management of the dying process is evident. Conflict between parties involved in the decision-making concerning pursuing or withdrawing treatment is common. It is particularly apparent between teams requiring negotiation

and diplomatic maintenance across the boundary of intensive care. Cross-cultural confusion, varying levels of education and information and idiosyncratic or individualistic styles of decision-making and withdrawal practices by intensivists are also determining factors in aggravating miscommunication and gaps in care. Misalignment between medical and nursing practices create gaps in communication and lead to fragmentation of care and confusion about best care.

Output: The project has so far produced two prize-winning posters (one national and one international), two international conference presentations, an invited article for the international journal *Communication and Medicine* and a submitted article to *Social Science and Medicine*.

Selected Publications and Presentations

Iedema R, Sorensen S, Braithwaite J, Turnbull E (in press). Speaking about dying in the Intensive Care Unit, and its implications for multi-disciplinary end-of-life care. *Communication and Medicine*.

Iedema R, Sorensen R, Braithwaite J, Flabouris A (in press). The teleo-affective limits of end-of-life care in the intensive care unit. *Social Science and Medicine*.