

Hospital Policy on Medical Futility — Does it Help in Conflict Resolution and Ensuring Good End-of-Life Care?

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Abstract

Introduction: This paper aimed to ascertain if hospital policy on medical futility helps in conflict resolution, and in ensuring good end-of-life care. **Materials and Methods:** Literature on the subject published in the last 5 years was identified through Pubmed, and those with empirical data pertaining to the outcomes of interest were examined. A systematic analysis was not possible as papers varied greatly in aims, designs, outcomes and their measures. Instead, the outcomes of representative papers were described and discussed. **Results:** There is a widespread use of policies and guidelines based on the concept of medical futility. Conflicts are rare and appear to arise primarily from the manner in which policies are implemented. End-of-life care appears to be improving as evidenced by a significant number of deaths occurring following: (i) discussions involving patient, family, healthcare team members; (ii) cessation of intensive care and (iii) cessation of institution of palliative care. Deaths are increasingly taking place in the presence of family and outside the intensive care wards. Finally, post mortem audit of processes and practices indicate (i) compliance but in a limited manner with policies and recommended guidelines, (ii) family satisfaction and (iii) identify areas where improvement in end-of-life (EOL) care can be effected. Key areas are in improving education of, communication with, and documentation by all stakeholders. **Conclusion:** Hospital policies on medical futility have helped to resolve conflicts and improve end-of-life care. Prospective, multicentre and controlled trials will be useful in determining the value of specific interventions, obtaining generalisable data and facilitating implementation of better end-of-life care models.

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Introduction

The concept of medical futility has been present since antiquity, and traditionally marked the shift in the primary goal of care to providing physical and emotional comfort. Only by following the declaration of futility could interventions be designed to relieve distress and pain for the patient, and bringing a sense of peace, and dignity be instituted.

The widespread availability and use since the sixties of mechanical ventilation accompanied by the dominance of the ethics of beneficence led to an unwritten rule for resuscitating everyone who developed cardio-respiratory failure, and a tendency among physicians to unilaterally pursue and persist in aggressive therapy. However, the poor outcome of the majority of such interventions and the rise in

the dominance of the ethics of autonomy manifested in an increasing desire in patients and their family to participate in decision-making, and to resort to litigation when necessary. This led to the questioning of the inappropriateness of such interventions, and was followed by the development of the concept of brain death, and policies on cardiopulmonary resuscitation, and guidelines for their implementation.^{1,2}

Further development of technology supported the interventions to support almost any kind of organ failure. The demands by patients and family for such interventions and the persisting fear of litigation led to the reawakening of the concept of medical futility in the late eighties when it became apparent to clinicians, ethicists, patients and family members that in spite of the technological advances, there is always a stage when it will become apparent that

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medical interventions will not reverse the disease and dying process, and that a declaration of futility was necessary for goals of care to change. The ethical justification was the absence of beneficence produced by the interventions, the creation of harm, the respect of the autonomy of the patient or surrogate to be able to decide when enough is enough, and the autonomy of the physician to be not compelled to administer interventions believed to be futile. Important, but not critical, was the ethical imperative of distributive justice. Limited resources had to be made available to those who would benefit and physicians could not be compelled to institute or continue with interventions that they considered to have no benefit.³⁻⁶

There has been a variety of definitions of futility based on qualitative and quantitative paradigms, but all are value-laden and not a single one adequately described all aspects of the concept.⁷⁻¹⁰

Nevertheless, institutional policies were formed and implemented as physicians and institutions needed a framework within which they could safely work and make decisions.¹¹⁻¹⁴

However, the initial tendency for these decisions to be made unilaterally by physicians with little or no patient family participation, the marked variations that accompanied the subsequent care processes, the differences in expectations of outcomes, the differences in how benefits and harms are valued, the difficulties in dealing with uncertainty of outcome, the denial of illness severity, the transference by physicians and families of their own values and perceptions to the patient, and real and perceived legal barriers led to occasional but highly publicised conflicts.¹⁵⁻¹⁷ In addition, a universal consensus on what constituted medical futility was never achieved. In response, the American Medical Association on Ethical and Judicial Affairs changed the strategy by recommending a process-based operative definition which could be applied to the benefit of any individual patient.¹⁸ The process included steps aimed at deliberation and resolution including all parties, steps aimed at securing alternatives in the case of irreconcilable differences, and a final step aimed at closure when all alternatives have been exhausted. In 1999, Texas was the first state to adopt a law regulating end-of-life decisions, providing a legislatively sanctioned, extrajudicial due-process mechanism for resolving medical futility disputes and other end-of-life (EOL) ethical disagreements. After 2 years of experience, they reported on their success with practical resolution of conflicts that had risen and recommended that others consider developing similar laws.¹⁹

Over the last decade there has been widespread adoption of this strategy worldwide.

The experience gained from the institution of process-

based definitions especially that gained from managing the complex cases with multiple stakeholders and uncertain prognosis, and the resulting conflicts have led to a deeper understanding of concepts and improvements to the process. These include the acceptance that medical futility is fundamentally context dependent, resting upon the judgments that have to balance effectiveness, benefits and burdens, and simultaneously respect the uniqueness of each clinical encounter. This requires the establishment of guidelines that are patient-centred, focus more on a fair process rather than on matters of definition, and enable benefits to all affected parties.²⁰ As conflicts are often due to breakdowns in communications and loss of trust, there is a need to introduce into the process a third-generation of interventions that aim to prevent or mitigate conflicts by enhancing communications and allowing the conduct of negotiations at the bedside.²¹

In this paper, I shall review the recent published empirical findings on the role of process-based hospital policies on medical futility in helping conflict resolution and ensuring good end EOL care.

Materials and Methods

Using the following terms: “medical futility”, “hospital policy”, “conflict resolution” and “end-of-life care”, the Pubmed database was searched. Papers published in the last 5 years and which examined the outcomes with empirical data were identified through manually examining the abstracts. The identified papers were then studied.

Results

Studies that were identified were all retrospective and observational; they varied markedly in the variables examined and the manner of examining, and hence a systematic and structured summary was not possible. Instead, the key findings of each were presented and assuming a certain degree of reproducibility a summary was developed and discussed.

Drawing from nonsystematically derived sample of published studies and commentaries, the manner in which conflicts over end-of-life care were resolved in the USA were described by Luce.²² The author concluded that conflicts were rare as most families and physicians agree about how patients should be treated at the end of life. He found that mediation between physician and family complemented by consultation from and, occasionally, adjudication by Ethics Committees was usually successful. He highlighted the likelihood of malpractice suits when physicians acted unilaterally. The suits, however, were rarely successful as long as the physician practised within the institutional futility policies and practice guidelines.

A review of the differences and similarities between North America and Europe in the forgoing of life sustaining treatment noted that in Europe, there was less use of standard and formal procedures, strong restraints and reserves to accept surrogates as decision makers, and a preference to a paternalistic position of physicians.²³ The average percentage of intensive care unit deaths preceded by decisions to forgo life sustaining treatment in the US was about 70%. Except for northern Europe which had similar proportions, the average for most European centres was well below 50%. The authors concluded that respecting patients and surrogates autonomy could also mean allowing them to leave decision-making to physicians, and in the process protecting the former from the distress and guilt that often accompanies such decisions. Such “paternalism” could be more “compassionate and philanthropic”.

A review from Victoria, Australia of the end-of-life processes and family involvement through a chart audit of all deaths in a 12-month period in a metropolitan intensive care unit reported that death was expected in 60 of the 70 patients, not for resuscitation documented in 58 cases (85%), family discussions were held in 63 cases (90%), withdrawal of treatment occurred in 34 patients and that death occurred within 6 hours in 31 of them.²⁴ Withdrawal of ventilator support occurred in 24 patients and family members were present at the time of death in 46 patients. Family concerns about the end-of-life care were documented in only one instance. The authors concluded that in their unit, end-of-life management was a consultative process and that death was quite predictable.

At the John Hunter Hospital, New South Wales, Australia, in a 6-month period between 2005 and 2006, 47 ICU patients had withdrawal of interventions.²⁵ Their charts were audited and a structured interview was conducted with the intensivists documenting the withdrawal. The authors found that 55% of ICU deaths were due to treatment withdrawal. Treatment failure or futility was the predominant reason cited for withdrawal. There were no cases of conflict between the medical team and the family. They also reported that a high level of confidence in end-of-life (EOL) decision-making existed among the intensivists, and that the latter rated consultation with intensive care unit (ICU) colleagues as the most helpful factor in decision-making. They concluded that they had demonstrated the feasibility of developing a quality improvement tool for EOL decision-making and applying it in the intensive care setting.

Noting that palliative care was often not in the end-of-life care of many surgical patients, a group of surgical intensivists and palliative care specialists from the US using a modified Delphi technique, identified the following 5 triggers for initiating palliative care consultations.²⁶ These were family requests, considered or declared futility,

family disagreement, patients advance directive or death were expected during the same SICU stay or a SICU stay >1 month.

Practices vary all over the world. In a prospective study of 45 admissions to a Lebanese intensive care unit over a 1-year period, treatment limitation occurred in 9.6% of all admissions.²⁷ In 38%, it was withheld and in 7%, it was withdrawn. Nursing staff and families were not involved in 26% and 21% respectively; in 23%, the actions were not documented and in 63%, there were no pharmacological interventions to increase sedation or pain relief. The authors attributed cultural differences and the lack of formal guidelines to the ethical limitations of their decision-making process.

The consequences of the absence of a policy on medical futility affecting end-of-life care was illustrated by the findings from an Indian non-profit private tertiary institution that provided advanced neonatal care under conditions of resource scarcity.²⁸ They had a high threshold for treatment initiation and continuation, and complex, inter-related socioeconomic reasons influenced specific treatment decisions rather than predicted clinical survival.

In another study involving newborns, the authors examined deaths of newborns in 1988, 1993 and 1998 at the Department of Paediatrics, University of Chicago.²⁹ Almost 50% of infant deaths followed withdrawal or withholding of interventions without receiving chest compressions or epinephrine boluses. They observed that when cardiopulmonary resuscitation (CPR) was withheld, it most commonly occurred in moribund infants who were already receiving mechanical ventilation and pressure support. However, physiologically stable infants in whom mechanical ventilation were withdrawn for quality of life reasons accounted for only 3%, 16% and 13% of NICU deaths in 1988, 1993 and 1998, respectively. They also observed that the median and average day of death for 100 non-survivors who received full intervention did not differ significantly from the 78 non-survivors in whom interventions were withheld. They suggested that the circumstances of dying in the NICU were more accurately reflected when a distinction was made between those who were physiologically stable and those who were already moribund.

The acceptance of palliative care for newborns leads to the consideration of medications to relieve physical distress. The type, doses and reasons for administering medications as part of end-of-life decisions in Dutch intensive care units were established through a medical file review of 340 newborns with preceding end-of-life decisions and interviews conducted with 110 of the 150 involved in their care.³⁰ Analgesic and sedative use increased from 224 to 292 newborns after the end-of-life decision; medication

dosage was increased in 94 when death was imminent and in another 110 whose prognosis was poor; only in 4% was hastening of death the reason, but in 55%, the reason was not documented; neuromuscular blockers were administered to 16% to stop or prevent gasping. The authors concluded that hastening death through medications was not prevalent but were concerned that insufficient documentation of considerations leading to increase of medication hindered external review.

The awareness and agreement of American paediatricians and nurses in critical care and other subspecialties with existing principles recommended by professional societies, ethics institutes and the courts for the withholding and withdrawing of life support, the provision of adequate analgesia and the inclusion of parents in decision-making were ascertained through a survey.³¹ The authors concluded that there was a need for more hospital-based education and interdisciplinary and cross subspecialty discussion on complex paediatric end-of-life cases. The education was to focus on establishing appropriate goals of care, pain management, pharmacological relief of distressing symptoms and medically supplied nutrition and hydration, and the use of paralytic agents.

The need for sensitivity and regular good communications between parents and medical and nursing staff when implementing the process of withholding or withdrawing of care in children is emphasised by the authors from the United Kingdom.³²

An important source of conflict in end-of-life care is that which develops between healthcare providers. One potential area is the extent of involvement that nursing team members have in end-of-life care decisions and implementation. This is an area with limited published literature.

A questionnaire survey of 419 European critical care nurses attending a critical care conference with a 39% response rate revealed a good involvement in EOL care (92%), decision-making (73.4%), commitment to family involvement in decision-making (78%), a high degree of consensus on open visiting and continuing pain relief (>90%), and some division of views on the need for deep sedation and continuation of nutritional support (44% and 41% agreeing, respectively).³³ The authors concluded that the use of formal guidelines and education may increase nurses' involvement and confidence with EOL decisions.

Underlying attitudes, if not allowed to surface, can be another source of conflicts among care givers. A questionnaire answered by 155 Turkish paediatric intensive care nurses showed that about two thirds did not agree with the withdrawing and or withholding of futile interventions.³⁴ Almost 70% indicated that intravenous nutrition needed to be continued at all costs. In the presence of futility, they

either would respond maternally or leave decisions to parents; joint discussions were not common. An education in ethics was thought to be essential by the authors.

Understanding patient perspectives and preferences is a vital part of customising end-of-life care. A cross-sectional observational descriptive questionnaire study of 100 Saudi Arabians who had been on haemodialysis for more than 2 years revealed that the majority had little or no knowledge about life support means and had authorised their physicians to decide for them in this area.³⁵ Only 22% believed that this decision should be done by their family members and 77% preferred to be at home when a hopeless stage was reached.

The prevalence, content, communication and implementation of written institutional policies on medical end-of-life decisions were recently examined by means of literature review.³⁶ The authors identified 19 studies, 2 of which were from Europe and the remainder from North America. They noted that documentation focused on procedural and technical aspects of DNR policies, but little attention was paid to defining specific roles of stakeholders and to exploring the ethical basis of the policies. Empirical studies about the implementation of ethical policies were scarce. The investigators concluded that further research is needed to establish if these policies were contributing to better end-of-life care.

Another paper discusses the end-of-life care policy through examination of the international literature and what is currently presented within UK policy.³⁷ The authors concluded that end-of-life care (EOLC) literature and national policy can assist with the complexities by providing a framework for physicians involved in palliation services.

The difference made to practice by end-of-life care policies was empirically examined by a review of the health records of 310 adults who died in 3 acute care facilities in a major urban centre of a Western Canadian health region.³⁸ The authors found that few providers followed policy directives regarding the use of care plans, terminology or documentation of discussion of treatment plans with patients or families. They concluded that a significant gap existed between institutional EOL care policies and practice in this particular health region, and which required clinically relevant policies that will enhance patient care to be devised.

As part of a systematic review of end-of-life care, satisfaction was evaluated as an outcome of healthcare interventions at the end of life.³⁹ The domains of satisfaction with end-of-life care were evaluated through examining qualitative literature. The literature on palliative care was also reviewed to determine among other things, effectiveness of collaboration and consultation. They identified 21 relevant qualitative studies, 4 systematic reviews and 8 additional intervention studies. From the qualitative

studies, they identified the domains of accessibility and coordination, competence including symptomatic treatment, communications and education, emotional support and personalisation of and support of patient's decision-making. For collaboration and consultation interventions, 8 of 13 studies showed a significant effect on satisfaction. A meta-analysis found that palliative care and hospice teams improved satisfaction, although most studies did not include satisfaction as an outcome. They concluded that researchers had conceptualised satisfaction in palliative care, and different types of interventions could improve satisfaction. They opined that that more focus on satisfaction elements might improve the effectiveness of end-of-life interventions and their evaluations.

From the literature published in Singapore, 5 studies with empirical data on end-of-life care were identified. The earliest was in 1998 and studied the specific supportive measures instituted or withdrawn during the DNR period, and those in force at the time of death in a cohort of 102 patients who died between 1996 and 1997 in the geriatric department of a tertiary hospital.⁴⁰ During the DNR period, about one third of patients had one or more of the following interventions instituted: oxygen therapy, nasogastric tube feeding, intravenous fluids, blood investigations, opioid use and antibiotic use. Interventions withdrawn were intravenous fluids (36%), hourly vital signs monitoring (22%), antibiotics (14%), high dependency care (12.5%) and nasogastric feeding (7%). It was observed that the DNR status was decided late in the course of the patient's illness and that the patient with a DNR status in force might still receive CPR.

Another study examined if the practice of forgoing life support (FLS) differed between the young old (range, 55 to 74 years of age) and the old old (>74 years of age) admitted to a medical intensive care unit.⁴¹ The authors found that illness severity as reflected by the APACHE II (M) score and the presence of a high-risk diagnosis rather than age predicted FLS orders.

A one-to-one semi-structured interview was conducted on a convenience sample of 46 elderly Chinese men and women attending a daycare centre.⁴² Their median age was 71 years and the predominant religion was Buddhism/Taoism. There was a clear preference to know the diagnosis and prognosis of a terminal illness; 84 and 77%, respectively. The attending doctor was preferred by 60% to reveal diagnosis and or prognosis. About 84% had not heard of the Advanced Medical Directive (AMD) but 37% agreed that making an AMD was necessary. About 50% preferred that the doctor be their surrogate decision maker and 35% would choose family member as their surrogate. Half were of the opinion that euthanasia should be allowed. About two thirds wanted CPR, mechanical ventilation, nasogastric

feeding and intravenous hydration. About 40% wanted renal dialysis. It was concluded that the need existed for closer communication between older persons and their medical carers with regard to end-of-life care. The attending doctor appeared to have an important role in this area.

The most recent study examined the use of artificial hydration in terminally ill cancer patients during the last 48 hours of life.⁴³ There were 238 patients with a median age of 62 years and a median duration of palliative care of 5 days. Artificial hydration was administered to 59% of the patients. A significant difference did not exist in the incidence of symptoms related to hydration status or in the pattern of medication use when those receiving artificial hydration were compared to those who did not. There were no differences in their survival and it was concluded that artificial hydration during the last 48 hours of life had made no major difference to these terminally ill patients on palliative care.

The influence of opioid use on survival of terminally ill cancer patients was retrospectively studied in the same cohort of patients previously described.⁴⁴ The median daily doses of oral morphine were 48 mg and 57 mg at 48 hours and 24 hours, respectively before death. Patients with spinal metastases needed higher doses while those with increased age or lung metastasis needed lower doses. There were no significant differences in survival analysis between those who were on opioids and those were not on oral opioids. The authors concluded that opioids were safe medications for symptom relief in terminally ill patients during the last days of life.

Discussion

This enquiry has indicated the widespread use of policies and guidelines based on the concept of medical futility. All studies provide data that indicate the overall usefulness of policies and guidelines, though design considerations limit the pooling of their data and generalisability of their conclusions. Two studies^{27,28} specifically report the difficulties and consequences faced by the absence of formal policies and guidelines, and provide valuable negative evidence that supports the hypothesis that hospital policies and guidelines do help in conflict resolution and improving end-of-life care. All the studies provide data that remind us of the complexities and contextual nature that surround the care that each person needs at the end of life and the competencies, cooperation, collaborations, comprehensiveness and commitment, that is required from the institution, care providers, family and patient. Education of all parties, communications between all parties and documentation by all parties appear to be the most common area where improvement is needed. In Singapore, it will

be very helpful if current practice in restructured hospitals and care provider, patient and family perspectives of EOL care are determined by a multicentre prospective study.

To determine the effectiveness of responses to the challenge produced by the desire to provide good end-of-life care, it is necessary that minimum data sets of measures are developed. Some of the key variables that could be included include the patients physical comfort, the patients spiritual belief and psychological well-being, the patient and families access to information and control over treatment decisions, family psychological, spiritual and social well-being, continuity of care across providers and care settings, and family adjustment after death. The sources of this information could be general administrative data, data from end-of-life care providers, retrospective assessment of data and population surveys. The strengths, limitations and key variables that can be obtained from each of these sources have been recently described.⁴⁵

Conclusion

In conclusion, this review has revealed evidence that hospital policies on medical futility do help improve EOL and reduce conflicts. High quality, multicentre, prospective and comprehensive studies are next required to provide reliable and generalisable data that will enable cost effective implementation of interventions that yield the greatest benefit.

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