Original Research Paper

Need For Integration of Clinical Ethics Services as a Global Best Practice in End-of-Life Care in Oncology: Suitability of The Nijmegen Methodology in the Indian Context

Lal P Madathil[1], Arpita Gur[2], Russell Franco D'souza[3], Princy Louis Palatty[4], Manjeshwar Shrinath Baliga [5]

[1]Department of Education, International Program, International Chair in Bioethics, World Medical Association Cooperating Centre (Formerly UNESCO Chair in Bioethics University of Haifa) Directorate of The Asia Pacific Division, Education Department and Global Network of Bioethics and Medical Education, 71 Cleeland Street, Melbourne 3175 Australia.
[2]The Bioethics SAARC Nodal Centre, International Network of Bioethics at Amrita Institute of Medical Sciences, Kochi, Ernakulam, Kerala, India.
[3]Department of Periodontics and Implantology, Aditya Dental College, Beed, Maharashtra University of Health Sciences, Maharashtra.
[4]Department of Pharmacology, Amrita School of Medicine, Amrita Institute of Medical Sciences, Amrita Vishwa Vidyapeetham, Ernakulam, Kerala.
[5]Education & Research Unit of Bioethics at Mangalore Institute of Oncology, Pumpwell, Mangalore, Karnataka, India.
Corresponding Author: Princy Louis Palatty
E-mail: princylouispalatty@gmail.com

ABSTRACT

The Nijmegen method of ethical case deliberation is one of the ways of reflecting, clarifying, evaluating and making decisions about moral problems, conflicts and dilemmas in the clinical settings. It is a hybrid concentration of relevant ideas from different normative ethical traditions applied to clinical practices. As a team multidisciplinary based deliberation, the method involves a professional ethicist serving as both a critical tutor and a facilitator in the process of deliberating and arriving at most ethical decision in clinical dilemmas. In such process, the Nijmegen method is not a democratic replacement of the decision and responsibility of the healthcare team. Rather it helps to motivate rational decisions and reasoned responsibility in healthcare through consensus building which does not attenuate moral uprightness. The Nijmegen method is part of the healthcare process and aims at improving communication among patient, family and the healthcare team as well as enriching the decision-making process. It is a promising method in resolving moral dilemmas in healthcare, especially in multicultural societies. Besides enhancing the quality and transparency of the decision-making process, ethical case deliberation on the ward using the Nijmegen method has prospect of serving as a baseline in guiding through similar dilemmas in the future.

Keywords: Nijmegen Methodology, Global Best Practice, End of Life Care, Oncology.

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Introduction

Integrated cancer care pathways are globally recognised as best practices adapted to provide most effective and optimum care to the patients in the field of oncology [1-2]. This involves multidisciplinary team of health care workers supporting the patient and family during the continuum of care [1]. Today global standards of care and facilities are available at tertiary cancer centres in India, which includes cutting edge technology as in linear accelerators, robotic surgery platforms, and access and availability to newer chemotherapeutic and immunotherapeutic agents [1]. The supporting teams of diagnostic services, nursing, counselling, and other health care services in India are at par with many western centres. However, oncology services in India face challenges from distributive justice with regards to being in a low- middle income country and resource allocation which is a known fact. One of such best practices in oncology clinical services practised at many global centres is clinical ethics services (CES) which acts as an integral part of multi-disciplinary team to address ethically difficult situations such as in end-of-life decision making process. CES as a part of hospital clinical service is still in its infancy in India as clinical ethicists trained through structured educational programs in bioethics are few in number and onco-ethics needs more attention in this regard.

Moral case deliberations are contextual; differ from case to case and have its socio-economic and religious dimensions [3]. Several methods have been proposed; normative and hermeneutic; decision-oriented and reflective [4-5] proposed a two layered approach. Later 2003, Steinkamp and Gordijn [6] compared four methods of ethical case deliberation such as Clinical Pragmatism, the Nijmegen Method, the Hermeneutic method, and Socratic Dialogue. Steinkamp and Gordijn, (2003**)** [6] opined that if moral case deliberation is both a social process and an ethical argumentation, then the choice of a certain ethical method as well as the method's ability to relate argumentation to the particulars of a case matters.

In this article, the Nijmegen Method of moral case deliberations detailed by Steinkamp and Gordijn (2003**)** [6] is used to illustrate issues in terminal care in an Intensive Care Unit (ICU**)** at a Cancer hospital in a south Indian city. This city is multi-cultural and multi-linguistic with people belonging to major religious sects making the scenario complex. In critical care settings the patient centric approach gets shifted to a family centred approach [7] and often the clinician is faced with ethical dilemma between deontological concepts instilled in him as a doctor and the challenges based on utilitarianism. From the patient's family perspective, ethical dilemma demands further clarity of individual case scenarios and in search for clarifications, they would discuss it with senior non-treating clinicians as in explained in this case. This approach is similar to the two layered approach proposed by Steinkamp and Gordijn (2001**)** [5]. This article further analyses the adaptability this MCD methodology based on ethical theories embedded in this clinical scenario; and the clinicians' moral duties which are framed within the Ethical guidelines of Medical Council of India [8].

Case In Discussion

An 80-year-old male patient reported to the casualty of a Cancer hospital in South India on an emergency basis. The hospital records showed that he is diagnosed with Non-Hodgkin's Lymphoma (NHL**)** of Central Nervous System (CNS**)** and under treatment for past 5 years. He received 5 cycles of chemotherapy and received 36 GY/20#/4 week's radiation and was under review. When presented to casualty, he was in a state of altered sensorium and drowsiness. He was shifted to ICU and underwent investigations. Further his CT and MRI brain scan showed ill-defined infiltrative enhancing lesion in the frontal lobe involving the corpus callosum and at the dorsal aspect of pons causing significant perilesional oedema and mass effect which was consistent with lymphoma along with age related atrophic changes. A Neurologist's opinion was sought at this stage.

Medical Oncologist consult was sought who suggested High Density Methotrexate therapy plus or minus high dose Cytarabine. However, as patient's general condition was poor and biochemical profile suboptimal for the said treatment, chemotherapy was not pursued. He was started on supportive therapy with IV antibiotics, IV fluids, and other supportive measures. During his stay in ICU, on the 10 days, he developed persistent cough and aspiration was suspected. After 14 days,

he had excessive secretions and there was absence of cough reflex and the Pulmonologist suggested endotracheal intubation. His family was consulted and explained the need for endotracheal intubation and ventilation; but his family did not give consent. As his condition deteriorated further, the hospital decided to inform his family regarding the poor prognosis and inform any relatives who wish to see him before he dies. Seeing the effort taken by the patient to breath, the newly arrived family members asked, *"if anything else can be done to make him comfortable as they can't see him suffering"*. They wanted opinion from the Critical-Care Specialist whom they previously refused the intubation regarding the possibility of an elective tracheostomy procedure. Patient was attended by Physiotherapist and Clinical Pharmacologist during his stay at the hospital.
Oncology team discussed the scenario with a non –treating doctor with interest on ethical issues and interacted with the family members on the condition of the patient and the advanced nature of disease. Family was told that patient many do not recover from the trauma from tracheostomy which was later concurred by the Otolaryngologist. The family felt they should do something to help the patient and the non-treating doctor was available for the family to help in decision making procedure. The chief Oncologist informed the family that *"if a tracheostomy could have saved the patient, we would have done it before"*. As the patient belonged to a religious sect who believed in continuous prayer till the last minutes of the patient, the corridors of the hospital became crowded which was against the hospital protocols. Poor prognosis was discussed with patient relatives, and they wanted to take him home and a home nurse was arranged through a local agency. Patient was discharged against medical advice as per the wishes of the family.

The Nijmegen Method of Ethical Case Deliberation

1. What is the moral problem?

The moral problem is if the treating doctor should always agree for the family's wishes in terminal care situations while choosing the treatment plan and discharge.

2. Analysis of Facts

2.1 Medical dimension

The critical care specialists in Oncology constantly balance the risk-benefit ratio in terms of future quality of life expected for the patient and try to minimize the aftereffects as far as possible. In this case the patient has NHL affecting CNS and the Neurologist confirms with the Oncologists regarding the advanced nature of disease as evidenced in MRI scan. As a patient of 5years, doctors were aware about deteriorating condition of the patient. Along with the neuro-radiological images, signs/symptoms shown by patient, biochemical profile, and GCS Score convinced the medical team that the patient has got just a few more days to live. As his cough reflex was diminished, in fear of aspiration pneumonia, endotracheal intubation was suggested but the family didn't consent. Later when consideration for a tracheostomy procedure was raised, the patient was not medically fit to withstand the procedure from anaesthetic point of view which was considered an unwarranted intervention in this case.

2.2 Nursing dimension

As a regular patient over the past 5 years, the nursing staffs were familiar with the patient and family. As per their religious belief there were many visitors crowding in front of ICU and nurses had the difficult task of controlling them in emotionally charged up situations. Another issue was the need for regular suctioning of throat with which patient was very uncomfortable and he used to refuse that was documented in nurse's notes. Logistically it was not permissible to allow entry of bystanders to the hospital premises at non visiting hours.

2.3 Patient's values and social dimension

Patient is retired businessman with 4 children who stayed with him in a traditional joint family. He belonged to a closely knit family and society where religious beliefs played a major role. This was reflected as active support and togetherness in difficult times and the religious head of the community had a say in critical decision-making process. Financial aspects were not a concern as they were wealthy people who opted for private payment option at the hospital.

2.4 Organisational dimension

Being a healthcare establishment in a multicultural and multi-linguistic society poses challenges to the organisation while considering ethical issues and without hurting the sentimental values of the patient and family. Language barrier can act as a challenge, as word to word translations during healthcare delivery often create confusion with the stakeholders involved. The clinical setup has patients fully paying for their treatment and those who are covered under different insurance schemes making the ethical deliberations substantiated. Being in a developing country, the organisation is faced with financial challenges while dealing with insurance patients. In this case the family could afford the treatment and they wished to do whatever needed without any financial constraints.

3. Assessment

3.1 Well-being of the patient

As this patient was a regular attendee at the hospital, he was familiar to the treating team and family understood that the doctors were focussing on the well-being of the patient in a utilitarian manner. The endotracheal intubation offered by the clinician initially was reflecting the concept of beneficence [9] and at a later stage when the patient's condition worsened, the family asked for aggressive measures which the doctor declined considering the poor health illustrating a non-maleficence approach [9] reflecting a patient centred deontological approach. Though the family tried to repeatedly demand during the course of hospital stay, the clinicians took a stand for the best interest of patient.

3.2 Autonomy of the patient

Patient was in phases of being conscious, semiconscious and unconsciousness during the hospital stay. Patient felt using suction to clear his airway will lead to bleeding which was one of the reasons why family declined intubation. In terminal care scenarios in Oncology, the death of the patient is expected and is explained to family. When the patient was not in a position to give consent for the procedures, the doctors wanted to follow deontological approach to safeguard the autonomy [9] of the patient.

3.3 Responsibility of the health care professionals

The multidisciplinary team consisted of Emergency Physician taking charge of the patient from casualty to ICU, Medical, Surgical and Medical Oncologists, Neurologist, and Radiologist assessing the advanced nature of the disease; a Pulmonologist and Otolaryngologist advising on need for the intubation; a Critical-Care Specialist and Physiotherapist regularly attending the patient while in ICU along with the nurses and medical social worker .A senior hospital administrator (non-treating doctor) was available during working hours to discuss family concerns who acted as a link person during times of decision making. There was no official translator as family could understand local language.

4. Decision-making

In this case there were three situations wherein decisions were taken. Initially when the family declined to intubation, the patient was conscious and his autonomy along with the families' concerns were accepted by the clinical team. However, they were warned of the possible deterioration of the condition. Later when the family requested for surgical intervention, the critical care physician and anaesthetist were not sure if the patient would recover from the procedure. The family's concerns were expressed to the senior administrator and their sense of doing everything they could be possible to keep them happy (utilitarianism) was not agreed by the doctor. However, after 20 days in hospital, finally the decision was taken to take patient home. In terminally ill cancer patients, this option is given and the family is required to fill in a declaration form "Discharged Against Medical Advise" (DAMA**)** .

4.1 Recapitulation of the moral problem

While terminally ill patients are treated in ICU, there are constant deliberations on the part of doctors and family to make sure that the patient's best interests are respected, and he gets justice in the clinical situation. However, when there is a shift from patient centric to family centric approach, the decisions and actions of the stake holders may conflict. Though there were conflicting deliberations, hospital focussed at the best interest of patient whereas family 's concerns were addressed too.

4.2 Unknown details

Family was aware of the terminal illness but when more relatives came to see the patient, it is possible that elders from community put pressure on family to *"do more for the mental peace of all"*. As a common practice they decided to take patient home for terminal care. It is possible they felt "more at home" by doing so and staying back at the hospital without any active intervention wouldn't have made any difference to the outcome in this case.

4.3 Arguments

Ethical deliberation, as proposed immoral liberalism by Gracia [10] aims to find the best course of solution to each ethical case through analysis of the problem embedded in its whole complexity. These demands analysing the scenario and understanding conflicting values and its consequences, thus allowing for the possible courses of solution to be equated. In Indian context, the clinicians work within the national stipulated framework laid down in Professional Conduct, Etiquette, and Ethics Regulations [8] which focuses on a patient centred approach. These regulations have legal binding in court of law and strongly emphasises on the deontological approach. Deontological ethics of duty [11] through the non –consequentialist actions emphasise, that what a doctor as an individual in healing arts should do in relation to another person (a patient**)** in a particular situation (during his/her illness), regardless of the effect on the common good. The consequences of a deontological action may be right for the individual but may not produce a good outcome for the whole population which represents family, relatives and society in general. The analysis of the case shows that the doctors through their actions insisted to protect the four principles of healthcare ethics; autonomy, beneficence, non-maleficence, and justice presented by Beauchamp and Childress [9] which created conflicts with patient's family.

Whereas patient's family and relatives took collective decisions during course of treatment (declining treatment, and further demanding for interventions**)** and finally decided to get discharged against medical advice and their actions aimed at "what they believe is right" reflecting a utilitarian approach [12]. By their actions on the overall good of society (family and relatives), rather than of individual (patient**)** within it, they followed this 'consequentialist' moral approach as it assumes that the results of actions can be predicted (eminent death of the patient), and therefore the ends justify the means (discharge against medical advice), if it is for the greater good. As there were no financial constrains in this case, the utilitarian dilemma of the organisation did not come into the deliberations [13].

4.4 Decision

"Quality of life" in terminally ill patients is a highly individualistic concept, making it difficult to define as it depends on factors such as the patient's age, life course and healthcare pathway before admission [14]. In ICUs, patients may not be capable of expressing themselves and this precludes any communication or consent for care which might reflect their wishes to start on complex therapies [15]. In such cognitive handicap [16] the only solution for the physician is to include the patient's family in healthcare decisions, firstly to avoid any unreasonable obstipation, and secondly, to ensure that patient's wishes and values are respected. This puts significant burden on the family along with psychological distress and hospitalisation of a loved one. During this "post-intensive care syndrome" [17] which family goes through, they have to take decisions on the well-being of patient which can be emotionally challenging. During this confused state of mind, conflicts between family and clinicians can takes place.

In the context of "family-centred care", the family may be related or unrelated to the patient who includes persons who provide support and with whom the patient has a significant relationship; and respects and responds to individual families' needs and values [18]. By aligning with their needs, the clinician takes decision based on scientific medical knowledge within the code of conduct and legal framework as seen in this case.

4.5 Evaluation

When moral ethical problems arise in clinical settings, in order to reach decisions, deliberation is considered as the cornerstone of a participative clinical ethics. Here though an expert ethicist was not available, a senior administrator assumed the role of moderator in multidisciplinary deliberations reflecting a two-layer model of clinical ethics [5] making it a robust methodology in ethical deliberation which aims to amalgamate the strengths of the model of La Puma and Toulmin (1989) [19] and the approach of Wilson Ross (1990) [20]. Here the deontological approach of the clinicians conflicted with utilitarian outlook of family and illustrates how paradigm shift from patient centred to family centred approach add new dimensions in ethical deliberations. Availability of a trained clinical ethicist or ethics consultants can provide better ethical guidance or advice [21] or constituting a clinical ethics service can discuss case scenarios among a group of experts [22] or adapt to moral case deliberations (MCD**)** where a facilitator leads a group dialogue among a multidisciplinary team of healthcare professionals about an ethical dilemmas with the use of a specific method [23].

Conclusions

Though most of the Indian hospitals have hospital ethical committees, an ethical consultant is not available and often a multidisciplinary approach is utilised to deal with clinical ethical issues. In Indian oncological settings, whenever ethically difficult clinical situations arise such as in end-of-life situations, generally the senior most or treating consultant through expert consultation facilitates resolving the decision-making process in ethical dilemma. This involves a specialist in oncology using his prior knowledge and experience to deliberate on ethical issues in a paternalistic manner. Inclusion of a clinical ethics expert as part of the multidisciplinary team will make the integrated care pathway more robust in alignment incorporating global standards in Indian context.

Declaration

This narration is based on authors experience at teaching Bioethics. The identity of the patient, clinical setting and confidentiality is respected and are not divulged in this article. The study has been approved by Mangala institutional Ethics Committee [MIEC/V6.2/53 (on 19th March 2022)] Mangalore, Karnataka India.

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